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The last months of living: an ethnographic study of the trajectories of illness and care for patients with advanced cancer in Greece

Anagnostou, Despina

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Author: Despina Anagnostou

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**The last months of living: an ethnographic study of the
trajectories of illness and care for patients with
advanced cancer in Greece**

Thesis submitted to King's College London for the degree of Doctor of Philosophy

Despina Anagnostou

Supervisors: Professor Irene J. Higginson, Dr Theresa Wiseman, Professor Alison
Richardson, Rev. Dr Peter Speck

King's College London, Florence Nightingale, School of Nursing and Midwifery

May 2013

Abstract

Context: There is little institutionalised palliative care ¹in Greece; hence most patients with advanced cancer die in hospitals with unrecognised palliative care needs. There is little evidence on the care these patients receive. Patients' perspectives and experiences of the illness and care, and their preferences on issues around death and dying have not been examined within the Greek context.

Aim: To explore in-depth the care received by patients with advanced cancer in Greece, and how they and their families experience the illness and care throughout the last months of life.

Methods: A prospective longitudinal, qualitative approach was adopted, employing an ethnographic methodological framework. Thirteen patients with advanced cancer were followed until death, from the point they came into contact with either one of two medical wards or a day clinic in an oncology hospital in Athens. The data were collected using participant observation, semi-structured interviews and discussions. The patients, 34 family members, and 32 health professionals involved in their care were interviewed (total 75 hours) and observed (total 830 hours). Data were analysed in both Greek and English, using thematic network analysis and case study analysis.

Results: Six men and seven women (patients) took part in the study, age ranging 30-75 years. Primary diagnoses included breast, lung and colon cancer. They were followed for 40 days to six months prior to death. Twelve out of the 13 died in the hospital (one died at home); their last admission ranged 10-70 days. Care focused on cure and prolonging life until the late stages of the disease, allowing little opportunity for transitioning to a palliative phase. Decision-making was doctor and/or family focused. The patient's voice was expressed through families. When patients chose to be actively involved, they did so through: a) planning care near the end of life, b) maintaining their role within the family, and c) assuring the space and time for their dying preparation. Dying trajectories were dependent on illness progression and

¹ Little Institutionalised palliative care in Greece: No palliative care services provided by the health care system. Not as yet governmental regulations /law about the provision of palliative care. Additionally, palliative care is not recognised as a specialty in Greece

doctors' attitudes; decision-making of care; symptom control; preferences for care and priorities of life, which shifted over time for patients and families; and patients and families values and attitudes towards death and dying. Patients' wishes for symptom relief increased as the illness progressed, whilst their focus shifted from the illness to the relationship with their loved ones, often resulting in changing preferences in support of their families' wishes. Near death, patients actively negotiated space and time for preparing to die, and performed dying rituals.

Families proved to have a central role in care provision. Members with a dominant role within the family most often adopted a decision-making role, whilst others retained the care-giving one. As the illness progressed, the focus of family's decision-making changed from cure to care and the symptom burden increased. Also, in cases where the decision maker within the family changed during the illness trajectory, the decision-making shifted to the preferences of the new decision maker. All patients expressed a preference to die at home. Most families changed their preference from home to hospital death due to lack of health care support at home.

Conclusions: The study showed the all importance of the interplay between decision making, illness progression, awareness of dying, family dynamics and their change over time in shaping patient trajectory at the last months of life. A framework of mindset orientation of goals and priorities is proposed which may provide a new prospect for approaching trajectories in palliative care.

In Greece, the journey of advanced cancer patients over their last months of life is shaped by a combination of factors including doctors' attitude towards cure rather than care; the lack of symptom control; the lack of availability of home care services; families' resources to advocate for the patient and the role of the patient within the family. Preferences and choices over care changed over time for some patients and their families due to these factors. For palliative care to develop within Greece, the reasons behind these attitudes need to be further studied and challenged, and suitable training developed. Also, proper multi-professional teamwork, an integral component of palliative care, needs to be developed.

Candidate's statement: origins of the thesis and my contribution

My experience as a nurse over ten years in Greece prompted me to enrol in an MSc, with a focus to Palliative Care, in 2003. Working in a neurosurgical and medical ward, in one of the main hospitals of Athens, I was faced many times with caring for terminally ill patients. As there is no institutionalised palliative care in Greece, it is extremely common for cancer patients to die on the medical wards of general hospitals. Specific palliative care needs associated with the experience of advanced cancer are unrecognised and untreated. I realised that this group of patients was often neglected, as health care in these settings was oriented towards cure rather than care. On many occasions, I felt helpless in trying to provide care for advanced cancer patients, as well as in trying to provide guidance to my colleagues. At that point, I decided that I needed to extend my knowledge of palliative care. During my MSc studies, I understood the importance of research in developing appropriate palliative care in different contexts. Looking at the Greek research evidence at the time, I was faced with a dearth of studies exploring issues related to Greek patients. By then (2004), I decided to enrol in a PhD, having secured a State scholarship from Greece. I decided to pursue a study looking at the nature of care and its experience by patients with advanced cancer in Greece, with the long-term goal of improving their care.

I designed the methods and managed the conduct of all stages of the study. Initially, I explored possible fieldwork places and carried out a three-month pilot study in an oncology hospital in Greece to assess the setting, establish fieldwork relationships, and test my role within participant observation and the interview approach. This experience was crucial in shaping the study and increasing my understanding of ethnographic procedures. I recruited all participants for the study and followed them until death. I handled the research contacts with hospital authorities, ethics committees, health professionals, families, and patients. I collected, transcribed, translated and analysed the data in all phases. I disseminated the findings at national and international conferences as well as local services within Greece and the UK. The findings of this study have informed the development of a home care service in Athens

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I remain determined to change practice in a country that has little or no palliative care. I believe that this will begin to change, albeit, slowly, however it will need robust research and determination from clinical colleagues to accept that change is needed. Thank you.

To my father

Picture 1-1: Still life, Penelope 2011



Epimythium

«Ο θάνατος, για να τον μελετάς, έχει το εύρος της ζωής που την ζεις. Έτσι τα δύο μπροστά σου γίνονται ένα.» (Δ. Λιαντίνης, Πολυχρόνιο, p. 17)

"Death, in order to study it, has the breath of the life you live. Thus, the two of them become one in front of you. "

1. Introduction

1.1 Origins of palliative care

Caring for people who are dying is an inevitable task for most professionals working in health and social care. Nevertheless, it was only in the last four decades that the needs of patients with a terminal illness started to be recognised and addressed. During the 1950s, clinical oncology was showing little interest in the care of those dying from cancer, with the focus on curing. The evolution of palliative care started in the 1960s with Dame Cicely Saunders, who was instrumental in drawing attention to the end-of-life care needs of patients and founded St Christopher's Hospice, the first modern hospice. Since then, the care of patients with advanced cancer and management of their symptoms during the illness has moved towards the centre of oncology care (Clark, 2007).

The success of St Christopher's was remarkable, and it soon became the incentive for a 'gold phase' of hospice development. In the 1980s, the UK saw 10 hospices open. Hospital palliative care teams were pioneered in the UK in 1976 at St Thomas' Hospital. Between 1982 and 1996, the number of hospitals with either a multi-professional palliative care team or a specialist palliative care nurse increased from five to 275. Additionally, two leading UK charities were vital in generating change - Macmillan and Marie Curie.

1.2 Palliative care globally

The importance of palliative care for patients was recognised by the World Health Organisation (WHO); it provided with the first global definition of palliative care stressing its relevance to patients not responsive to curative therapy (WHO, 1990). The WHO approach to palliative care has now been extended to the physical, emotional, and spiritual needs of the patient, and the similarities and opportunities for cooperation among those working with different diseases are emphasised. It has broadened in that it no longer considers just the patient, but includes considerations of health and well-being of family

members, and of patients' carers. Palliative care also extends beyond the period of care for the patient and includes support and counselling for the bereaved. These concepts are captured in the most recent WHO definition of palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2002).

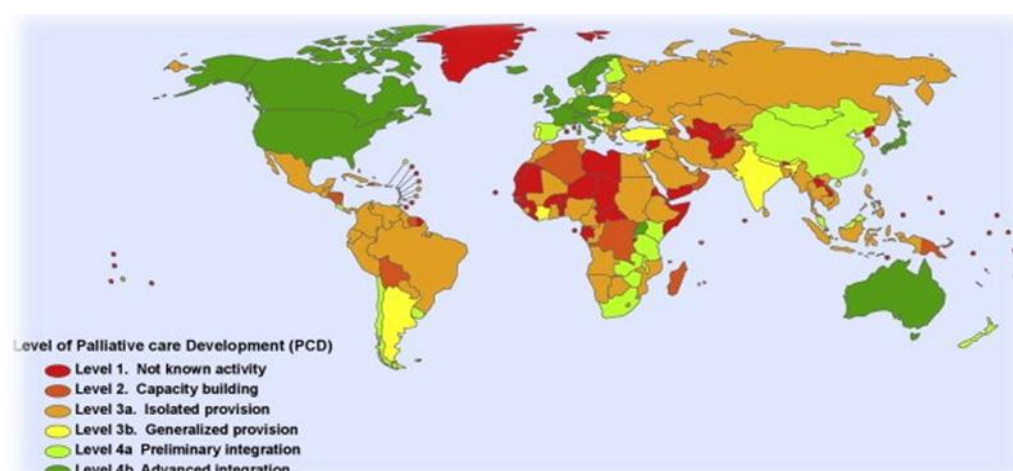
Over time, different models of service delivery have been developed and implemented throughout the countries, each having advantages and disadvantages (von Gunten, 2002). Palliative care is provided by teams working in hospices, specialists palliative care units, home care services and day care centres (Sepúlveda et al., 2002). By 2000, there were more than 6560 such teams in 87 countries around the world. More than 3600 of those teams were in North America; 933 were in the UK, and over 350 in Australasia (Finlay et al., 2002). The European Association for Palliative Care (EAPC) Taskforce on the Development of Palliative Care in Europe reported a variety of services developed within Europe. For example, in 2007, the UK, Germany, Austria, Poland and Italy had a well-developed and extensive network of hospices. Other countries, with France being the stronger representative, adopted more the model of hospital care teams. Day care centres are mostly found in the UK with hundreds of these services currently in operation (Centeno et al., 2007).

Despite the development of palliative care globally, there is still a formidable disparity in palliative care delivery across Europe and the world. The Worldwide Palliative Care Alliance (WPCA) argues that whilst more than 100m people annually would benefit from hospice and palliative care, less than 8% of those in need access it (Lynch et al., 2011). Two recent documents highlight the disparities in palliative care globally whilst mapping the levels of palliative care development and the end-of-life-care provision (Lynch et al., 2011, Economist Intelligence Unit, 2010). Nevertheless, the limitations of both reports

should be taken into consideration when evaluating their findings. In the WPCA study, the way that services are counted is problematic, because of the adoption of two systems: by the provider and service. Hence, a comparative worldwide analysis might be compromised. Both the mapping of levels of palliative care and the Quality of Death Index rely heavily on interviews and self-report by key persons in each respective country, which might have, introduced bias (Lynch et al., 2011, Economist Intelligence Unit, 2010). Lastly, experiences and outcomes for patients and families were not included within the indicators of the quality of end-of-life care. Nonetheless, these two reports are indicative of the current knowledge on the state of palliative care development in the world.

According to the WPCA report in 2011 (Lynch et al., 2011), 136 of the world's 234 countries (58%) have one or more hospice/palliative care services established – an increase of 21 countries (+9%) from a previous project in 2006 (Figure 1-1). The most significant advances have been reported in Africa and the Middle East. A considerable number of countries still have no hospice palliative care services and global development is described as patchy. Advanced integration of palliative care within the wider health services has only been achieved in twenty countries globally (Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, the UK, the USA).

Figure 1-1: WPCA palliative care development, all levels (n=234 countries) (adapted from Lynch et al., 2011)



The Quality of Death Index measured the environment for end-of-life care services across forty countries (Economist Intelligence Unit, 2010). Countries were scored across four categories: Basic end-of-life care environment; availability of end-of-life care; cost of end-of-life care and quality of end-of-life care. The researchers used interviews with experts and reviewed existing research on the quality of end-of-life care. The UK, Australia and New Zealand scored the highest in the overall ranking, whilst Brazil, Uganda and India were the lowest. The UK leads the world ranking in terms of quality of end-of-life care (this includes indicators such as public awareness, training, availability, access to painkillers and doctor patient transparency), with many nations lagging a long way behind, such as Greece (27th), Portugal (31st), and Turkey (34th).

Few countries, including high-income countries, have incorporated palliative care strategies into their overall healthcare policy (Australia, UK, Mexico, New Zealand, Poland Switzerland and Turkey) - despite the fact that, in many of these countries, ageing populations mean that the demand for end-of-life care is likely to rise sharply. Globally, training in palliative care is rarely included in healthcare education curricula. Institutions that specialise in providing palliative and end-of-life care are often not part of national healthcare systems, and many rely on volunteer or charitable status. Only eight countries ranked as excellent in painkillers provision (Australia, Canada, Denmark, Luxemburg, Netherlands, New Zealand, Portugal and Sweden); 23 countries scored in the middle level and eight - including Greece – ranked poorly. India ranked the lowest.

Although more than half of the world's countries have at least one palliative care service, many countries still have no provision, and considerable increases are needed before palliative care is accessible worldwide. The WPCA recommends a deeper inclusion of palliative care into broader health policy, and the improvement of standards for end-of-life care. Specifically, it recommended that all governments should adopt the WHO definition for palliative care, integrate palliative care into their health care system, and support and work in collaboration with the non-governmental sector in the delivery of palliative care.

In 2007, the EAPC launched an initiative - the Budapest Commitments - in partnership with the International Association for Hospice and Palliative Care (IAHPC) and the WPCA, in support of the palliative care development across Europe and the world. This initiative gives each country and national palliative care organisation in Europe, the opportunity to define its own priorities and targets for the coming years. Five broad areas were suggested: drug availability, policy making, quality of care, education, and research (EAPC, 2010a). This way, each country will be enabled to measure its own success against its own priorities and goals, rather than against other countries, which might have, different agendas and resources. So far, 15 European countries have joined these commitments, including Greece (Furst et al., 2009).

1.3 Palliative care in Greece- recent advancements

According to the WPCA report, Greece belongs to the group of countries which offer isolated palliative care provision (3a in Figure 1.1), and this is characterised by a development of palliative care activism; inconsistent in scope and not well supported. Also, funding comes mostly from donors, and there is limited availability of morphine. In addition, a small number of palliative care services exist in nature and relative to the size of the population (Figure 1-2). Greece is the only European country with isolated provision of palliative care, holding the lowest level in Europe (i.e. 31.6%). Moreover, comparing to the prior report of 2006, Greece has not moved further in the development and integration of services. Interestingly, death rates in Greece fall into the same range as the UK 8-11.9 per million population. However, the UK is in the highest level of palliative care provision, belonging to the group of advanced integration of palliative care services into mainstream service provision (n=20 countries, with the group representing 8.5% of all countries), whilst Greece falls into the category of isolated provision.

Figure 1-2: WPCA palliative care development, level 3a: countries with isolated provision (n= 74) (adapted from Lynch et al., 2011)



Reflecting the results of the WPCA report the Quality of Death Index by the Economist Intelligence Unit (2010), presented Greece with the lowest overall scores in Europe (4.0) followed by Portugal (3.8) (Table 1-1). In terms of quality of end-of-life care, which had the higher weight (40% of the total score), Greece ranked 32 (score 3.4/10) and placed at the bottom of the European countries, alongside Italy (3.4, 32). However, Greece performed better at the basic end-of-life care environment, ranking 13/40.

Table 1-1: Greek scores and ranks in the Quality of Death Index by the Economist Intelligence Unit (2010)

	Score/10	Rank/40
Overall score	4.0	29
Basic end-of-life care environment	6.1	13
Availability of end-of-life care	2.3	27
Cost of end-of-life care	5.5	20
Quality of end-of-life care	3.4	32

The EAPC Taskforce on the Development of Palliative Care in Europe conducted a qualitative survey amongst boards of national associations - the Euro-barometer survey - aiming to identify the barriers of the development of palliative care in Western Europe (Lynch et al., 2010). Six significant barriers were identified: lack of palliative care education and training programmes; lack of awareness and recognition of palliative care; limited availability of opioids analgesics; limited funding; lack of co-ordination of services; and uneven palliative care coverage.

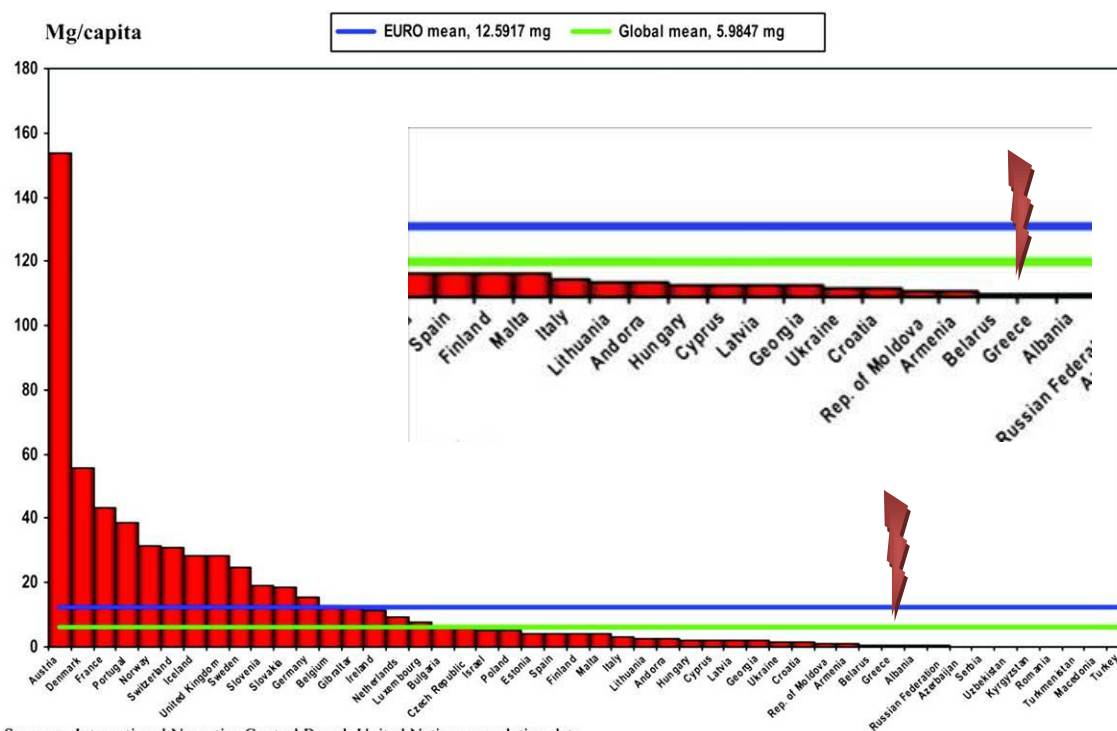
Based on those barriers and the Budapest commitments, I will now explore some of the reasons that might have kept Greece behind other European countries, and how the Budapest commitments might have impacted on the development of palliative care in Greece. Two national associations for palliative care were established in Greece, in 1998 and became EAPC members-the Hellenic Association for Pain Control and Palliative Care (HAPCPC) with Dr Mystakidou as leader and the Hellenic Society of Palliative Symptomatic Care of Cancer and non Cancer Patients (HSPSCCP) with Dr Vadalouka as president (Mystakidou et al., 1998, Vadalouka, 2009). They work in training, advocacy and promotion, by raising awareness of palliative care issues, and provide training in caring for terminally ill patients (Martin-Moreno, 2008). The national Greek associations for palliative care reported problems in three main areas: a. opioids' availability and prescription; b. palliative care education; and c. not recognition of palliative care as a specialisation for nurses and doctors. Three goals were set by the two national associations:

1. Improving access to strong opioids
2. Palliative care curricula included in all health care education
3. Development of specialised palliative care services across Greece (units, hospices, home care)- palliative care inclusion in the NHS

1.3.1 Opioids availability and prescription- goal 1

Excessive regulatory restrictions make it nearly impossible for Greece to achieve optimal relief of cancer pain. Greece is the only West-European country which requires physicians to receive authority to prescribe opioids. It is also the only West-European country that limits prescription to less than 21 days' supply of medication. Greek regulations forbid the provision for opioids prescribing in emergency situations. Oral methadone and immediate release oxycodone are not available in Greece. The availability of certain opioids in Greece has been related to cost issues. It has been argued that pharmaceutical companies are not interested in introducing different kinds of opioids because the markets are not profitable (Lynch et al., 2010). Excessive regulatory restrictions and cost issues make it nearly impossible for health professionals, families and patients to achieve pain relief, placing Greece at the bottom of morphine consumption in Europe (Figure 1-3).

Figure 1-3: European consumption of morphine (adapted from Cherny et al., 2010)



Sources: International Narcotics Control Board; United Nations population data
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2008

During January 2013, the leader of the home care team of Galilee spoke in the parliament, in an effort to influence policy with regards to opioids availability. A draft law was suggested in the parliament, requesting the increase of availability of the opioids for chronic and cancer patients, in accordance with the rest of the European recommendations (Personal communication with Dr. Tserkezoglou).

1.3.2 Palliative care education- goal 2

Insufficient focus on palliative care is given in both undergraduate and postgraduate medical education, resulting in a lack of university curricula and training programmes for health professionals and medical students (Lynch et al., 2010). However, commenting on the Budapest commitments, Mystakidou et al. (2008) stated that palliative care was included in the curriculum for medical and nursing students at the undergraduate level, as an elective module. Nonetheless, there was no relevant education provided for the other health care professionals (e.g. psychologists, social workers).

Responding to the Budapest commitments, improvements began in 2010, when the School of Medicine of the University of Athens in collaboration with the School of Nursing established the first MSc course called 'organisation and management of supportive and palliative care'; attended by 20 health care professionals every year (Mystakidou et al., 2010). Additionally, palliative care was included in the MSc studies of the School of Nursing, university of Athens, under the specialty of oncology and palliative care (Nursing-UOA, 2012).

1.3.3 Palliative care services- goal 3

Palliative care services are not yet established within the national health care system. All existing services are outpatient units and are supported by NGOs. Five NGOs are identified, all of which try to promote and deliver palliative care in Greece in collaboration with the two national associations of palliative care. Three of these NGOs are based in Athens (Agapan Foundation, Jenny Karezi Foundation and Parhsia), and the charity

Faros-Skopelos is based on a Greek island. Special attention should be given to the Merimna organisation, which is the only organisation focused on paediatric palliative care (Papadatou, 2001). Also, the metropolis of Mesogaias and Lavreotikis of the Orthodox Church is currently actively involved in establishing and improving palliative care in Greece (Galilee, 2012).

A few outpatient units in Athens provide symptom control to terminally ill patients; 85% of patients receiving palliative care have a cancer diagnosis and are linked to the main oncology hospitals in Athens (EAPC, 2010b). The first outpatient unit was established in 1993 with the support of the Tzeni Caraezi foundation and is linked with the 1st Radiology department, Athens Medical School, Areteion Hospital. In 2010, Merimna established the first paediatric home care team, linked to the two paediatric hospitals of Athens. The first home care team in the wider area of Attika - Galilee Palliative Care Unit - was established in 2010, funded exclusively by private donations and the local metropolis of Mesogaias and Lavreotikis (Galilee, 2012). In 2012, the team expanded to a day care centre, offering its services once a week. Most recently, a hospital palliative care team was developed - pilot phase- in the St. Savvas hospital in Athens. It should be noted that this mapping of services was based on personal communication with key consultants in Greece as there is not any formal registry for palliative care services.

The persistent efforts of the two national associations and some of the NGOs resulted in the enforcement of palliative care services (hospices- home care) in the national action plan against cancer 2011-2015 of the ministry of health (Action against cancer, 2008). However, no progress is achieved in recognising palliative care as a medical or nursing specialisation, despite efforts, resulting in a shortage of a skilled palliative care workforce (Lynch et al., 2010).

1.3.4 Public awareness

In Greece, people are not well informed about the discipline of palliative care. In the Quality of Death Index, Greece ranked poorly in the item of public awareness of end-of-life care; scoring 2 between 5 (highest ranking) and 1 (lowest) alongside Italy and Portugal (Economist Intelligence Unit, 2010). A few peculiarities in Greece might have contributed to this outcome. The existence of two national associations for palliative care might have created challenges in collaboration and co-ordination across services, organisations and efforts in establishing palliative care in Greece. In addition, it appears that there is no consensus for the Greek term of palliative care. Even though, the EAPC guidelines recommend the term '*anakufistiki frondida*' as the equivalent term for palliative care (Radbruch, 2009), two more terms were identified in the Greek literature to be used as equivalent terms: '*parigoritiki agogi* and *parigoritiki frondida*'.² On the other hand, both associations are committed in organising conferences, round table discussions, and public awareness events. Most recently, The National TV channel (NET) broadcasted a documentary presenting the work of the Galilee home care team and discussing the notion and principles of palliative care. (ET-1, 2012)

1.4 Research and palliative care

Palliative care research on patients' needs and experiences aim to promote person-centred care. Within palliative care, the experience of dying - hereby defined as the

² **Παρηγορώ:** [pariyoró]: To speak, to behave to someone with the intention to tone down, comfort his sadness, distress from something unpleasant that happened to him (Babiniotis G., 1999)

ανακουφίζω [anakuffizo]: To comfort, reduce the physical or mental pain. To remove someone's part of the physical pains or some weight of his burdening responsibilities, to help someone rest (Babiniotis G., 1999; Triantafilidis, M., 1965)

Φροντίδα [frondída]: the devotion of thought and action to something (e.g. health) due to interest, love, care/concern (Babiniotis G., 1999)

Αγωγή [ayojí]: course of treatment, therapy (Babiniotis G., 1999)

experience of living with, a progressive, incurable, illness and considerable disability - can be viewed as a natural and normal part of life (Byock, 1999). A patient-centred perspective can acknowledge the difficult medical issues involved, and the often distressing nature of a patient's experience, while not dismissing the potential value of this time in the life of the person and family (Lynn, 1997). Some of the features of patient-centred care are described as a response to individual needs, recognition of the central role of families and their support, valuing the knowledge, skills and resources which patients and families already have, involvement of patients in their care, and the provision of services that are culturally sensitive (Richardson, 2004).

Palliative care research has focused on examining the needs and experiences of palliative care patients (Carter et al., 2004, Teno et al., 2004, Murray, 2000, Donnelly and Walsh, 1996). Several dimensions of patients' experience such as symptom management, psychosocial support and care preferences are well explored in the literature (Aikman et al., 1999, Teno et al., 1999). Patients' needs have been examined through their own perspectives, their families' and health professionals' (Tassinari, 2003, Singer et al., 1999). Identified needs - physical, psychological, social and spiritual - have been included in several tools that measure quality of life for this group of patients (Bottomley, 2002, Steinhauser et al., 2000b). Quantitative and qualitative research studies have attempted to identify the determinants of QoL for terminally ill cancer patients with the goal of providing high quality of care (Pilkington and Mitchell, 2004, Kaasa and Loge, 2003, Cohen and Leis, 2002). Aspects of 'a good death' and factors that could influence the quality of dying have been suggested since 1960s (Kubler Ross, 1975, Glaser and Strauss, 1965), and systematically examined in recent years (Sandman, 2005, Powis et al., 2004, Steinhauser et al., 2002, Copp, 1998, Seale, 1998).

Monitoring health outcomes is essential for the development and maintenance of high quality patient care (Carr and Higginson, 2001). A variety of outcome measures are now available to palliative care professionals, enabling an assessment of the quality of care,

either prospectively or retrospectively by using proxies as sources of information (Aspinal et al., 2003, Hearn and Higginson, 1999). However, the wider social, cultural and structural context should be considered as factors that may influence the use of outcome measures in palliative care (Hughes et al., 2003).

Despite the focus of palliative care research on issues around patients' experiences, quality of life and quality of care, there is a lack of research that seeks to follow patients through their illness trajectory. This is concerning as it has been argued that patients' preferences, values and beliefs change during their journey through illness, especially when they reach the end of their life (Doyle, 1999, Hinton, 1994).

A few longitudinal studies have sought to explore the needs of palliative care patients. Researchers have tried to understand the meaning that patients give to their illness or life with advanced cancer (Yedidia and MacGregor, 2001, Carter et al., 2004, Thome et al., 2004, Murtagh et al., 2011). Most studies, however, were not concerned with how the nature of care might have influenced participants' experience. Two longitudinal studies have looked at the relationship of care provision and patient experience. Lawton (2000) was interested in the experience of the deteriorating body in relation to patients' identities and the provided care in hospice settings the UK.

The vast majority of the existing longitudinal studies have been conducted in the UK and US. There is a dearth of evidence on the care and experiences of terminally ill patients in the rest of Europe (Strang et al., 2004). The International Association for Hospice and Palliative Care (IAHPC) supports that each country should develop its own model of palliative care provision based on the needs of local patients and the resources available, and not be expected to copy models from other countries with different socio-economic conditions (IAHPC, 2004).

In Greece, there is a vast need to understand the barriers to developing and providing palliative care, the cultural issues associated with death and dying, which in turn might

influence illness trajectories, symptom burden and, ultimately, end-of-life care. Such knowledge may help to understand why Greece holds one of the lowest stages of development of palliative care in Europe, and why there is no institutionalised palliative care at present. Greek cancer patients are increasingly dying in hospitals (Mystakidou et al., 2009a, 2009b), whereas, in other parts of Europe, there is a clear shift towards home death (Gomes et al., 2012). There is little evidence on how advanced cancer patients are cared for, and most of the existing knowledge relies on cross-sectional studies (Alexopoulos et al., 2011, Mystakidou et al., 2011). The health care settings involved in the care of these patients, the nature of care provided, the health professionals' contribution, and the role of families remains unclear. Patients and families' preferences have been briefly touched through surveys concerned mostly with issues of disclosing information and euthanasia (Parpa et al., 2006, Iconomou et al., 2001).

Exploring the cultural issues related to death and dying, and the contribution of all involved parties (patients, families, and health professionals), is crucial in a country at early stages of palliative care development. The complexity of the experiences and the magnitude of the challenges for the provision of end-of-life care require a robust examination following patients' trajectories until their death; therefore a prospective longitudinal approach is proposed, employing ethnography as its methodological framework. This study aims to explore the nature of care that advanced cancer patients receive in Greece and also examine their experiences of illness and care.

This thesis consists of eleven chapters. Chapters 2 and 3 provide the background of this study. Chapter two presents a historical overview of the death and dying culture in Greece, whilst chapter 3 reviews the evidence on the culture of end-of-life care in Greece. Chapters 4 and 5 present the aim and objectives of the study, followed by the methods used to collect and analyse the data, alongside the ethical challenges involved. The results of this study are elucidated in the chapters 6, 7, 8 and 9. Chapter 6 introduces the context where patients' experiences and health professionals' attitudes and behaviours were

recorded; providing a description of two wards and a day care clinic. Chapter 7 presents findings related to the nature of care offered to patients and explores attitudes and beliefs of nurses and doctors in relation to death- dying and their role in decision making. The families' views and roles in the provision of care are subsequently presented in chapter 8. Patients' experience of their care and the level of their participation in decision making are explored in chapter 9. Patients' patterns of communication and longitudinal aspects of their trajectories are also explored. Chapter 10 discusses the contribution made by the results of this study against the existing research literature and the implications of the study for clinical practice, education, research and policy. Chapter 11 presents the conclusions drawn from the thesis.

2. Background I: A historical overview of death and dying in the Greek culture

*"It is discourtesy
to give Charos (death) hand-kissing"*

Elytis O (2002:394)

Because everyone dies, end-of-life care is among the most prevalent issues in health care in any culture. If we are to improve the care of dying patients, it is vital to have a clearer understanding of what patients, families and health professionals believe to be important at the end of life (Teno et al., 2001a, Steinhauser et al., 2000a).

The notions of 'good death' and 'good dying' have acquired several meanings in time and across cultures, shaping different attitudes towards death and the process of dying. Some of them are closely associated with religious and other cultural world views: sudden death in Ancient Greek context (e.g. Graves, 1970), dying without suffering in the Anglo-Saxon context (e.g. Saunders and Baines, 1983), dying in the hospital with the best medical support (e.g. Callahan, 1993), peaceful death (e.g. Seale, 1998), awareness and preparation for death in the Christian tradition (e.g. Field and Copp, 1999), remaining conscious and lucid while dying (e.g. Lawton, 2000), dying at home in family surroundings (e.g. Lawton, 2000), self-control in dying (e.g. Smith, 2000), finding a personal meaning on their own death in North American context (e.g. Steinhauser et al., 2000b), dying among the family in the Southern Europe's traditions (e.g. Fainsinger et al., 2003).

Although some argued that ideas about good death are in a lots of cases, closely associated with religious and cultural ideas about an afterlife (Walter 2003), most of the ideas found in palliative care fit with the postmodern value of individual control and of people fashioning their lives for themselves as they see fit , not following or adhering to any traditions or overall formulas for how to live one's life (Smith 2000, Clark 2003) Yet, cultural attitudes towards death and dying may influence patients' values and preferences

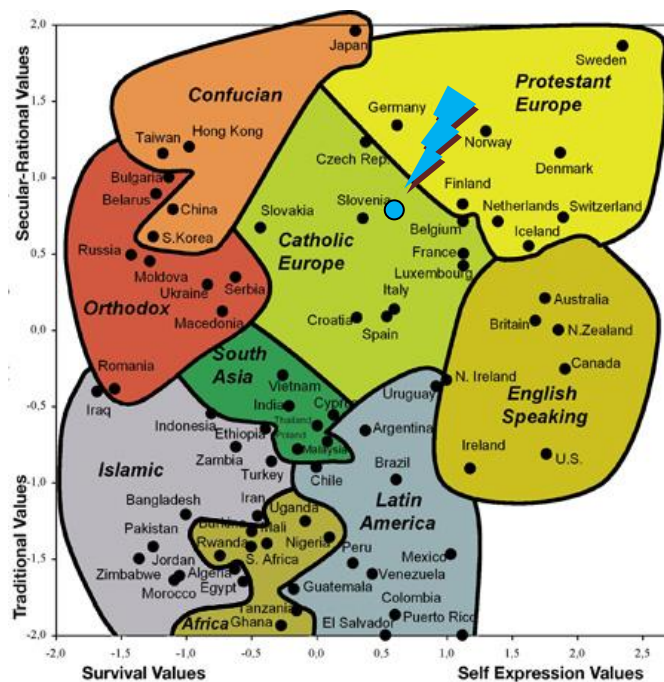
2. Background I: A historical overview of death and dying in the Greek culture

(Sandman, 2005). Seale (1998) argued that when patients, their families and health professionals face terminal illness, with limited options to cure and difficult decisions to be made, differences in cultural norms and values become particularly significant.

2.1 Cultural influences and health cultures

The World Value Survey (2009) was designed to provide a comprehensive measurement of the major areas of human concern, from religion to politics and social life across the world. It found that a number of basic values are shared between countries with cultural proximity, and not necessarily geographical proximity, although these two coincide to a large extent (Inglehart and Welzel, 2010). Countries of Europe were grouped into Catholic Europe, Protestant Europe, ex Communist- Orthodox and English speaking (Figure 2-1).

Figure 2-1: World Value Survey, cultural map of the world 2005-2008 (adapted by Inglehart and Welzel 2010)



Position of Greece highlighted in blue in the map, based on 2006 results

Two dimensions shape the map in Figure 2-1: a. traditional/secular-rational and b. survival/ self-expression values. Greece was not included in the report of 2010, but in the report of 2006 was placed within the catholic group and not the orthodox group, closed to Italy and Spain in terms of self expression values, but expressing slightly more

2. Background I: A historical overview of death and dying in the Greek culture

secular/rational values. Societies near the traditional pole valued religion more, compared to those closer to the secular values. They also emphasised the importance of parent-child ties and deference to authority, along with family values, rejecting euthanasia and suicide. South Europe seems to almost balancing between the two views. The second major dimension of cross-cultural variation suggested a polarisation between survival/self-expression values. English speaking and Protestant Europe seem to value more self expression values, whereas the South- Catholic Europe seem to consider both views, although self expression values begin to take priority. According to the survey, the priority given to self expression values emphasise quality of life and subjective well being, shifting away from the emphasis on economic and physical security. Self expression values give high priority to tolerance in diversity, individual control, and demands for participation in decision-making in social, economic and political life. However, given the current economical crisis, particularly in South Europe, values might shift towards survival values, as survival cannot be taken for granted anymore.

Distinctive health care cultures have shown to differ in meanings, priorities, attitudes and practices in end-of-life care. Indeed, studies which compared views and values between different cultures and countries revealed the importance and influence of those values to wishes decision-making and clinical practices (Gysels et al 2012; Cohen et al 2006; Fainsinger et al 2003).

Gysels et al. (2012), who conducted a cross cultural comparative review across Europe in relation to end-of-life care, reported clearly distinguishable national cultures of end-of-life care, with differences in meanings and priorities. The main areas of discrepancies reported were locus of control, death - acceptance of death and control- and autonomy concepts which in turn influenced clinical practices in relation to communication, information disclosure, involvement in decision making and euthanasia, reflecting the findings of the World Values Survey (Table 2-1). However, despite the national differences,

2. Background I: A historical overview of death and dying in the Greek culture

countries of South Europe shared some similarities in comparison to countries of North Europe.

Table 2-1: Main differences in attitudes towards death and dying between North and South Europe

	North Europe predominantly Protestant tradition		South Europe predominantly Catholic tradition	
Control	Internal locus of control-Individual control		External locus of control	
Concept of death	Life and death influenced by one's choices and preferences	Pro euthanasia Practice of advanced directives	Death is beyond someone's control. It is integral part of life, thus a natural stage in life	Against euthanasia Advanced directives not particularly used
Acceptance of death	Cognitive acceptance but not emotional or moral	Open communication Disclosing prognosis and diagnosis	Emotional and moral acceptance, not cognitive	Conspiracy silence Information disclosed to the family
Autonomy concept	Individual autonomy	Part of decision making; patient making choices	Individual belongs to the family	Family part of decision making; patient not able to turn information to knowledge

Western European literature (mainly Anglo-Saxon) often proposes that people's attitudes towards death develop primarily according to the value system of *individual control*. On discussing a good death, emphasis is given to patients achieving control over their dying and death (Smith, 2000, Clark, 2003). However, Stiefel and Senn (1992) noted that, in Southern European countries, cultural context influences many features concerning attitudes towards death and dying that are relevant to palliative care. The authors gave the example of disclosing the cancer diagnosis and prognosis in Spanish and German context. In Spain where cancer is still a taboo disease, health care professionals often establish a conspiracy of silence around the patient, under the umbrella of appropriate communication, whilst in Germany, the patient most likely is getting informed openly and shares decision-making over treatment and care options. This suggests that people's

perceptions towards death and dying may influence health care and palliation differently in different cultures.

In Orthodox Christianity and Roman Catholic tradition, life events and particularly death are considered to be beyond a person's control (Hatzinicholaou, 2003, Bates et al., 1993, Redfield, 1992). Death and life are conceived as part of nature's cycle, and humans are seen to have no choice but to accept it and make peace with it. In Protestant traditions, on the other hand, predominant in North America and Northern Europe, the prevailing view is that life events and circumstances are the result of an individual's own actions. Therefore, a 'good death' implies cognitive acceptance of that same death. Within this tradition, the individuals may influence or even control the manner of their own death (Callahan, 1993). This idea aligns with the work of Smith (2000) and Clark (2003) as previously mentioned. In the same tradition, patient's 'autonomy' always implies a cognitive acceptance of the impending death.

However, both 'cognitive acceptance' and 'autonomy' may be questioned in the cultural context of Southern Europe. In a cross-cultural comparative study of acceptance of death, Nunez Olarte and Gracia Guillen (2001) proposed a theoretical framework regarding perceived differences between patients and families in Spain and the US. According to their framework, Spanish patients and families were often not able to achieve cognitive acceptance of death (hence showing death denial). Instead, they accomplished an emotional and moral acceptance of death. On the other hand, according to Olarte and Guillen's findings, American patients and families often reached some acceptance of death at a cognitive level, but not emotionally or morally. The scoping exercise across seven European countries by Gysels et al. (2012), identified a similar difference between southern European countries (Italy, Spain and Portugal) and Northern European countries (Germany, Norway, Netherlands and Belgium). In South Europe, disclosure practices opposed the obligation to open information about diagnosis and prognosis - prevalent to

2. Background I: A historical overview of death and dying in the Greek culture

Northern European countries, suggesting that cognitive acceptance and autonomy in decision-making might not be considered essentials in caring for dying patients.

2.1.1 Greek patients in comparative studies between countries or ethnic groups

Four comparative studies which included a sample of Greek/Greek origin participants highlighted the cultural similarities in attitudes between Greeks and Italians, in contrast with English speaking (Australian, UK origin) patients. Kanitsaki (1988) examined the views of Italian, Greek-Australians and Chinese patients in Australia, and found that all these groups were not favourable to information disclosure. Indeed, it was revealed that they did not want to discuss issues around death. Even more, they perceived nurses who did so as giving up on them. Goldstein et al. (2002) explored the views and practices of Greek-Australians nearly fifteen years later. Fifty-eight first generation Australian residents, who took part in focus groups, revealed that as family members translated for the doctor, they commonly changed or soften the doctor's message without the patient or doctor knowledge in order to protect the patient. In the US continent, Mancuso (2009), discussed the difficulties of providing culturally sensitive care to Greek patients, drawing from a few clinical cases where disclosure of the terminal condition to the patient proved to be inappropriate.

An Australian population survey conducted by Foreman et al. in 2006 revealed place of birth and ethnic origin to be a predictive factor of preferred place of death in the general population of South Australia. The authors found that the people born in Greece/Italy or with Greek/Italian origins were more likely to favour dying at home comparing to those born in Australia or UK/Ireland who preferred to die in a hospice.

Reinhart et al. (2007) found some different results when grouping countries in relation to withholding and withdrawing treatment practices in European intensive care units (ICUs). They conducted a prospective observational study of ICUs in seventeen European countries, including Greece. The authors found, that, indeed, religious affiliation influenced

end of life decision-making across European ICUs. Specifically, they found that withholding treatment occurred more often than withdrawing if the physician was Jewish (81%) or Greek Orthodox (78%), whereas withdrawing occurred more often for physicians who were Catholic (54%) or Protestants (49%). No Greek physician had reported to have performed active shortening of the dying process (SDP) and only 23% agreed that a patient should be informed of the prognosis. Although, the results of this study might not be representative of the country (one to four centres took part per country), this was still a large prospective study of consecutive 3,084 patients, evaluating physicians' real practices, rather than relying on hypothetical questions.

What these studies suggest is that before decisions about patient care are made in Greece, what good death and dying represents to Greek people, ought to be examined.

2.2 Greek culture

The Greek civilisation, developed upon the ancient Greek Philosophy and the Orthodox Christian tradition. The Greek language is the testimony of the continuity of the Greeks through the ages. Customs performed since Homer (VIII century B.C) and Byzantine times (A.D IV-XV centuries), demonstrate the power of these two traditions in the daily life of the contemporary Greece (Psilaki and Psilaki, 2001). Beliefs about death, dying and grief in Greece are based both on the ancient Greek and the Christian Orthodox traditions (Mystakidou et al., 2003).

The Greek culture does not deny death as is often stated about the Anglo-Saxon culture (Sandman, 2005). Death is conceived as an integral part of the life cycle, and thus accepted and dealt according to the two major, yet opposing, traditions: Ancient Greek Philosophy and Orthodox Christianity (Table 2-2).

2. Background I: A historical overview of death and dying in the Greek culture

Table 2-2: Main differences in attitudes towards death and dying between the Ancient Greek and the Orthodox Christian Traditions

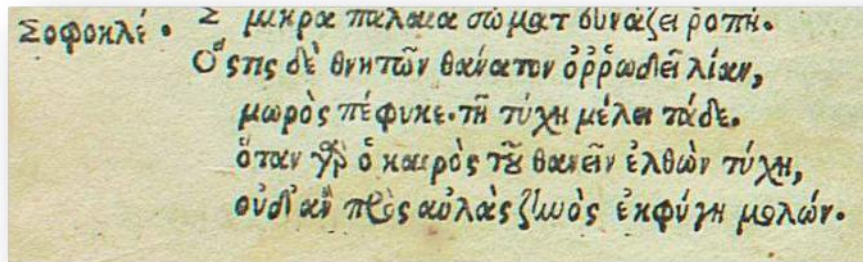
Ancient Greek Tradition	Orthodox Christian Tradition
<ul style="list-style-type: none">• Death is the end of life• Death is a final separation from the loved ones• A good death is a sudden death, where no pain will be acknowledged by the dying• There should be no fear of death because it is a natural and unavoidable part of the life cycle	<ul style="list-style-type: none">• Death is a change of life• Death is only a temporary separation, loved ones will meet again in the after life• A good death is a conscious death with time for preparation and contriteness• There should be no fear of death because life continues, even changed, and reunion with God and loved ones is expected

2.2.1 Ancient Greek tradition

In the context of ancient Greek Philosophy, death had a central role. Plato argued that ancient Greek philosophy was the study of death. Indeed, the ancient Greek philosophy was preoccupied with the ontological difference of human nature, of the awareness of death; the knowledge that all humans attain of their own death. In *Phaethon*, Plato argued that those who philosophise properly they exercise in dying (*Phaethon*, 63.b.4 – 69.e.2). He believed that through the kaleidoscope of death, people viewed their life in order to make it as far as possible correct (Liadinis 1992). This is apparent in the famous phrase of Solon to Croesus, the King of Lydia: *μηδένα προ του τέλους μακάριζε* (don't consider anyone happy before their death). Anyone's life would be judged by the manner he died; a good death signified a good life. Aristotle argued in his work of metaphysics that death defines the human existence, whilst Stoic philosophers argued that every human has a unique experience of death, which cannot be communicated. Hippocrates believed the acceptance of death would eliminate the fear of it (Spiridakis, 1972). Sophocles argued that the man, who is scared of death, is born witless. When the time comes, even if he shelters in the palace of Zeus, he cannot avoid it (Picture 2-1; Stobaei, 1536; 115, 12).

2. Background I: A historical overview of death and dying in the Greek culture

Picture 2-1: Sophocles about death in *Strobaei*, 1536; 115.12



In ancient Greek, the word 'end' (*telos*) had two meanings: termination and purpose. Based on this definition, Liadinis (1992) argues that death can be considered the termination, as well as the final goal of life. In ancient Greece, death was perceived as a process of transition from one state to another and conceptualised as a journey from this world to another- the underworld, deep beneath the earth- where the God Hades ruled the crowds of shadowy figures. Death was viewed as an unavoidable and natural part of the life cycle, natural as sleep. Homer claimed that Death and Sleep are twin brothers (*Iliad*, 17.672). The Greeks believed that at the moment of death the *psyche*, or spirit of the dead, left the body as a little breath or puff of wind (Graves, 1970).

Picture 2-2: Hermes with the twin brothers Thanatos and Hypnos (Death and Sleep) transferring Sarpedon the son of Zeus to Hades the world of the dead. Calyx-krater, ca. 515 BC; Archaic; red-figure, Metropolitan Museum of Art



2. Background I: A historical overview of death and dying in the Greek culture

Ancient Greek culture was oriented towards this world; any post-mortem benefits of religious beliefs and actions were only peripherally considered, if at all (Garland, 1985). Although the ancient Greeks developed a mythology of the underworld- its topography and inhabitants- they lacked myths that explained how death and rituals for the dead came to exist (Toohey, 2010).

Yet, death rituals which included funerary and burial practices in ancient Greece were attested widely. The deceased was prepared for burial according to the time-honoured rituals (Department of Greek and Roman Art, 2000). Ancient literary sources emphasize the necessity of a proper burial and refer to the omission of burial rites as an insult to human dignity (*Iliad*, 23.71). Women played a major role in funeral rituals. They conducted the elaborate burial rituals that were customarily of three parts: the *prothesis* (laying out of the body) the *ekphora* (funeral procession), and the interment of the body or cremated remains of the deceased. Lamentation of the dead is evident from the early Greek art at least as early as the Geometric period and continued right through the centuries. Depictions of it were found on vases and funerary plaques, decorated with scenes portraying the deceased surrounded by mourners (Picture 2-3).

Picture 2-3: Funerary plaque: ca. 520–510 BC Archaic, black-figure Greek, Attic Terracotta; The lying in state of a body (prothesis) attended by family members, with the women ritually tearing their hair



2. Background I: A historical overview of death and dying in the Greek culture

Following the *prothesis*, the deceased was brought to the cemetery in a procession, the *ekphora*, which usually took place just before dawn. Grieving the dead became an art form, expressing a way to make peace with events hard to comprehend in real life. Catharsis (= a complex psychosomatic process which purges an accumulated emotional tension) in the arts is associated with the relief of painful experiences like loss and death (Heron, 1977). This suggests an emotional approach of coping with death, since it is hard to rationally understand its reality.

2.2.2 Christianity era

Since the introduction of Christianity in the Greek culture in the A.D IV century, death received a meaning of hope.³ Resurrection of the dead and reunion with loved ones comforted the hopelessness of death (Liadinis 1992). This is the reason why cremation was not accepted by the Church, -as it was required that the physical body was not destroyed to dust- and is still not practiced in Greece nowadays. Byzantines believed that death was not the end of life but a change of life. As life was a journey, so death was a journey (Dennis, 2001). In A.D. 1360, Demetrios Kydones (in Dennis, 2001) composed a treatise to demonstrate that the fear of death was not rational. This was in accordance with the Greek philosophical tradition but employed other arguments too. In A.D. 800, Theodore of Studios wrote: “we will proceed along the same road which our parents have travelled before us...” (in Alexander p99). Even now, when somebody dies, people in Greece often say that ‘he left’ instead of ‘he died’. However, the pain of the loss was acknowledged and lamentation was incorporated within the funeral service. The importance of lamentation about the deceased is also apparent in two services related to the death of Jesus (Lamentations, Holy Saturday Orthros) and Virgin Mary (the assumption of Virgin Mary, Picture 2-4)

³ Christianity has come into close contact with Hellenism since the 2nd century A.D. However, Constantine the Great institutionalised their connection in the 400 A.D. and lent a lasting Greek influence to the church that emerged. This period is considered as the initiation of the Byzantine History Vasiliev, A. A. (1952) *The History of the Byzantine Empire*, 2nd English ed. Madison: University of Wisconsin Press.

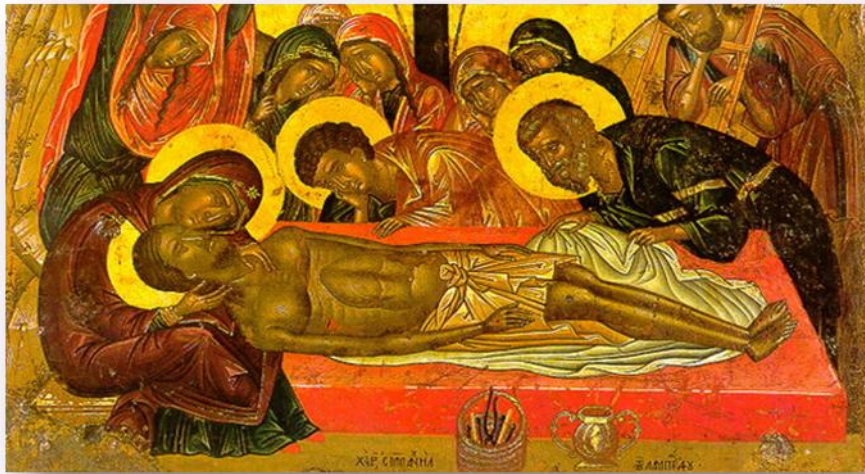
2. Background I: A historical overview of death and dying in the Greek culture

*When your mother saw you
brought to slaughter, Oh Lamb.
She was stabbed with painful torment; her anguished sobs
called the flock to join her bitter cries of grief*

*"Woe is me!" the Virgin
mourned through heart-breaking sobs.
"You are, Jesus, my most precious, beloved Son!
Gone is my light, and the Light of all the world!"*

(Lamentations before the Holy Sepulchre, from Holly Saturday Orthros)

Picture 2-4: Lamentations: Icon by Emm. Lambardos, AD 1640; Byzantine Museum of Athens



Some religious scholars have argued that chronic illness and the process of dying can prepare a patient for death through union with God (e.g. Archbishop of Greece, Christodoulos 2004). Therefore, a slow process of dying may be salutary for the patient's soul. In the service of 'artoclasia', the priest prays to the Lord "...for the protection of the Church from plague, famine, earthquake, fire... Civil war and sudden death" (Liturgy, 1995, p82), placing sudden death equally next to war and famine as a curse. It is not implied, though, that death should involve suffering. In the service of the Divine Liturgy, there is a prayer describing the 'good death': "... a Christian end to our life, painless, unashamed and peaceful let us ask our God" (Liturgy, 1995, p27).

2. Background I: A historical overview of death and dying in the Greek culture

Moreover, the Orthodox Christian religion does not accept euthanasia, believing that life is neither a commodity nor a personal right, but a divine gift. Perhaps this may explain the Byzantine attitude of reluctance to take a person's life, even when legally and morally permissible (Dennis, 2001). Finally, in its attempt to participate in the debate regarding the clinical definition of death, the Greek Church argues that medicine can only determine when the body is dead but not when the soul has left the body. When and how the soul is separated from the body, is a mystery. Consequently, the body should be buried not when clinical death is diagnosed but when decomposition is apparent (Hatzinicholaou, 2003).

2.2.3 Folk culture

Images of death are also apparent in the Greek folk culture. Death is often 'ugly', 'dark', 'chaos' and 'black'. "...my name is black cobwebbed earth...", and life described as "silver that is tarnished by death gold that rusts in death" (Koufos, 1970, p248) (Picture 2-5).

Picture 2-5: Spirits of dead people, carnival custom of Amfissa



However, what underlines death's dreadfulness is its absolute finality. The acceptance of the finality of death is expressed by the exhumation ritual: three to five years after death, the bones of the deceased are exhumed by relatives and a priest, washed in wine and stored in an ossuary (Dracopoulou and Doxiadis, 1988). Conversely, there is a sense that the dead live on. Some laments describe the deceased as having certain human needs,

2. Background I: A historical overview of death and dying in the Greek culture

mainly love and communication, which the bereaved try to satisfy through memorial services. Funeral laments, sung mainly by women dressed in black, have existed since Homer in VIII B.C. and are associated with the expression of grief and sorrow (Danforth, 1982). They express reciprocity and sympathy between the dead and the living (Spiridakis, 1972). Memorial services are often repeated so that the dead will not be forgotten and to remind the living of a reunion in heaven (Liadinis, 1992). At these services, the family boils wheat to be offered to relatives as a symbol of fertility and rebirth. This custom is linked to the ancient Greek ritual of '*panspermies*' given for the death, where the existence of the dead was negotiated (Panourgia, 1995).

The important role of death in the Greek culture has maintained its strict customs being performed throughout the centuries. These cultural elements provide meaning to death and enable grief to be resolved (Ikonomidis, 1966). Rituals around death and the dead body still play a significant role, particularly in rural communities. Friends, family, and neighbours say farewell to the dead following the burial tradition of Greece.

It should be said that the two traditions, ancient and orthodox, co-exist in Greece. Greeks are not affiliated exclusively either to one or the other. Greek culture has embraced both traditions by naming the first one as the tradition of ancient Greek Philosophy and the second one as the religion of Greeks (Panourgia, 1995). Both traditions are present in the folk culture as presented previously. Customs coming from both traditions are performed at the same time, even though they can conflict. To make it more complex, people are not necessarily aware of the provenience of their attitudes towards death and dying; and everything refers to tradition. It is difficult to identify one or the other tradition as more influential since social transformation is uneven; the society has not changed all at once or in one piece (Sutton, 2004). This means that different parts of Greece may have developed attitudes and customs referring more to one or the other tradition without a clear distinction (Seremetakis, 1991).

2.3 Contemporary challenges

Despite the centrality of death in the Greek culture, significant changes have taken place in contemporary urban Greece. Death in the Greek large cities has become increasingly distant from daily life. Health and youth are promoted, and attention is drawn away from illness and old age (Mystakidou et al., 2005). Expression of feelings of grief is not socially encouraged, and children are excluded from scenes where death has struck (Dracopoulou and Doxiadis, 1988). Dracopoulou and Doxiadis, two philosophers, argued that the Modern Greek society denies the existence of the dying process and, because of this, institutionalises it. The fact that most deaths increasingly occur in hospitals and that natural deaths are witnessed less frequently in large cities supports that argument (Mystakidou et al., 2009a, Dracopoulou and Doxiadis, 1988). Social changes, such as increased life expectancy, smaller families and older people living alone, are likely influences in the move of death into the hospital (Mystakidou et al., 2003, 2009a). For this reason (the westernised life style in metropolitan Greece), Mystakidou et al (2003) argued for an increasing need of developing hospices in Greece. There are indications that the Greek people who live in urban centres have started developing a more cognitive approach towards dealing with death. A link between socio-economic change and attitudes towards death has been also argued for Spain, affecting the younger generations (Nunez Olarte and Guillen, 2001).

Although Field (1994) and Evans and Walsh (2002) argued for a similar tendency regarding the place of death in UK, place of death trends have started reversing in the UK. Home deaths are slowly but steadily increasing from 18.3% in 2004 to 20.3% in 2010 (Gomes et al., 2012), something that is not happening in Greece (Mystakidou et al., 2009a, 2009b). Perhaps, the British policy pushing towards enabling more people to die at home has influenced this change (Department of Health, 2008).

The change of trends in the UK might suggest that a health care culture in relation to death dying and end-of-life care can influence the trends of people's preferences and priorities, as well as where they live and die. Understanding the particular cultural issues of end-of-life care and the possible diverse ways that end-of-life care is practised in Greece can be proved essential.

2.4 Summary and Conclusions

Conceptions of a good death and dying differ across different cultures. Despite national differences, countries of South Europe shared some similarities compared to countries of North Europe. Southern European countries share more traditional values - religion, family values, and authority, compared to secular values shared by the Northern Europeans. The above values influence their end-of-life care cultures, where family decision-making, opposition to euthanasia, reluctance of disclosure of prognosis to patients are some of the characteristics. In contrast, Northern European countries seem to share values of patient- autonomy and individual control, hence adopting open communication; patient participation in the decision-making and acceptance of euthanasia.

Greek culture around death and dying draws on two, opposing, traditions: Ancient Greek Philosophy and Orthodox Christianity. Although death has a central place in both of these traditions, different views have been proposed; ancient Greek culture considered death as the end of life whilst the Christian orthodox as a change of life with only a temporary separation from the loved ones. Both cultures argue against fear of death but differ in the notion of good death. For ancient Greeks, a good death was a sudden death whilst for the Orthodox Church a good death is a conscious death with time for preparation. Health care professionals should be cautious in generalising these values, as different parts of Greece may have developed attitudes and customs referring more to one or the other tradition. Also, current changes in the urban cities, suggest adoption of more

2. Background I: A historical overview of death and dying in the Greek culture

of western life style and values. Understanding the current issues of end-of life care in Greece might be equally essential in order to provide of culturally sensitive palliative care in Greece. Therefore it is important to explore the available Greek health care literature related to end of life care is considered.

3. Background II: End-of-life care culture in Health Care in Greece

3.1 Approach

A narrative review was considered, as this type of review is suitable to map evidence in a broad topic area which has not been reviewed before (Hammersley, 2002). This literature review intends to examine the end-of-life care culture in Greece, including attitudes of Greek people - public, patients, families and health professionals - towards death, dying and issues related to end-of-life care; hence its nature is exploratory and will apply an inductive approach. Thus, it will not specify concepts in advance, but instead will allow the phenomenon of the culture to unfold in the analysis of the literature.

Relevant evidence from Spain and Italy is considered, in search of similarities and differences between Greece and these two Southern European countries in order to give a more comprehensive view of South Europe with regards to the end-of-life care culture.

3.2 Methods

3.2.1 Search strategy

In order to identify as many relevant pieces of literature as possible, several electronic databases were searched: CINAHL (1982-2012); EMBASE (1980-2012), British Nursing Database (1946-2012), MEDLINE (1946-2012 & in process); PsycINFO and Cancerlit (1975-2012). The following search terms were used: [palliative OR terminal OR “end of life” OR end-of-life OR death OR dying OR “advance directive*” OR hospice* OR “supportive care”] AND [Greece OR Greek*]. In addition, the names of Greek academics who work in the field of cancer research and those with an interest in palliative care were used as search terms in order to retrieve more relevant publications. Hand search of key cancer/palliative care journals and Greek journals, as well as relevant reference lists were checked to identify any relevant peer-reviewed articles. Publications written by authors of

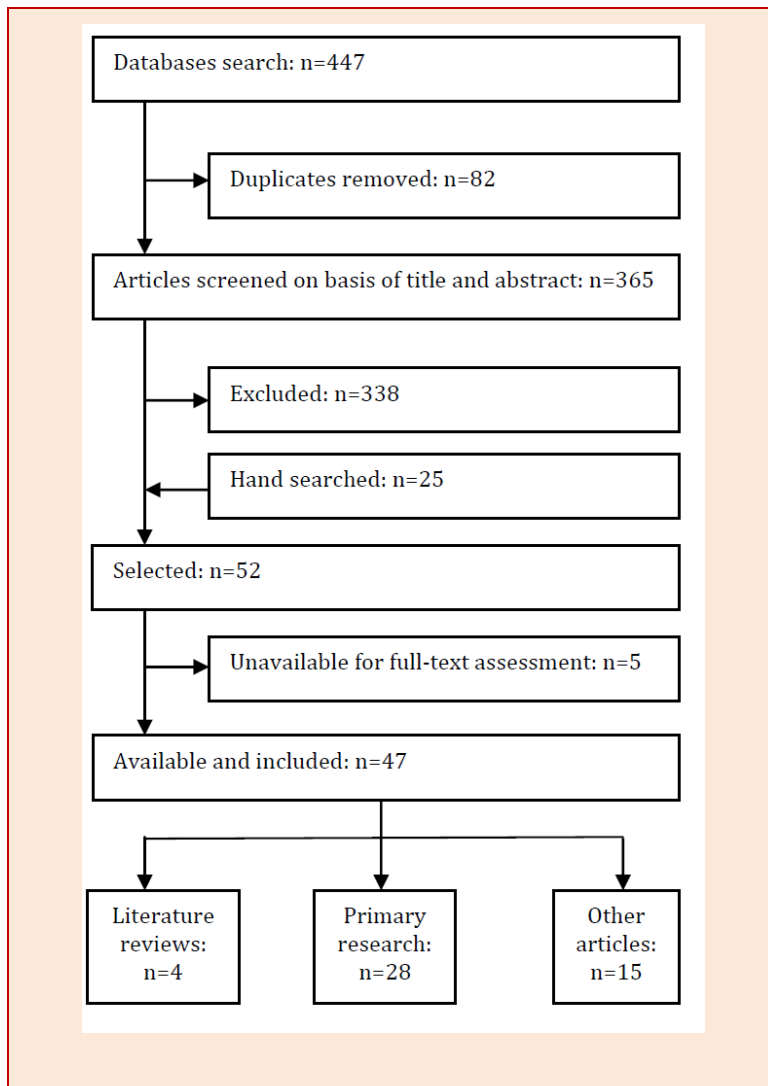
the articles deemed relevant were searched via authors' web pages. Some additional papers were retrieved after personal communication with key Greek authors in the field.

3.3 Results

A total of 365 papers for Greece were reviewed based on title and abstract for relevance after removing duplicates (Figure 3-1). Reviews and original research studies that informed socio-cultural issues in end-of-life care were included, whereas studies of clinical tools; symptom management; drug trials and intervention trials; and psychology were excluded. Literature reviews, with no evidence from Greek studies were also excluded. Lastly, some studies found in paediatrics, focusing mostly on grief and bereavement were excluded also for two reasons; a) this study is focused on adult care and b) is interested in socio-cultural issues of end-of-life care more, rather than psychological issues.

A total of 47 papers were included in this review. Four literature reviews; 28 original research papers and 15 other articles (i.e. commentaries, editorials, general and personal opinion papers).

Figure 3-1: Flowchart of included papers



Almost all papers focused on public, families, health professionals' attitudes, views and practices. Only three studies were found exploring patients' preferences of communication. With the exemption of one mixed method study, the rest original research papers were cross-sectional surveys, covering small numbers of participants and most of them local centres. The included papers were published during the period 1980-2011, whilst the majority covered the period 1995-2005. Most of the papers focused on cancer

patients and/or their families, or health professionals working with cancer patients; mostly oncologists but a few included generalists and anaesthetists. Palliative care for older people was reported once by Vadalouca (2006). Centres of recruitment for patients were hospitals or outpatient units of hospitals. The term used for patients until the year 2000 was advance cancer patients, and only from 2000 onwards the palliative care term is used to specify the population or the care provision.

This review identified three main themes in relation to end-of-life care culture: communication patterns in disclosing diagnosis and prognosis; end-of-life decision-making and treatment choices; and euthanasia.

3.3.1 Communication patterns in disclosing diagnosis and prognosis

The literature related to communication issues is focused on two areas: disclosing diagnosis and prognosis, found also later as '*breaking bad news*' and b) involved parties in the communication; the triangle of physicians-families-patients. Information disclosure appears to have been a consistent concern across the years, expanding from 1980 to 2005, covering each decade with at least two surveys. The latest studies found in relation to health professionals preferences, in communication of diagnosis and prognosis, were conducted in 2002 which raises questions of their applicability nowadays. No evidence was found to support any possible recent advancements or changes.

Doctors and nurses' attitudes on truth telling

During the 1970s, a public discussion on revealing the truth showed that physicians and surgeons supported the view of withholding the truth regarding diagnosis and prognosis, whilst theologians and lawyers maintained a view of disclosing the information to patients (Noussias et al., 1975).

Similar attitudes on withholding the truth from patients were expressed by physicians later in the eighties. Manos and Christakis conducted a survey among 110 Greek

oncologists working in cancer and university hospitals (1980). With a response rate of nearly 65%, they found that the 73% of the doctors rarely or never communicated the truth with their patients whilst only 5% prepared patients for their imminent death. A survey with a sample of 120 physicians by Dossios et al (1986) found similar attitudes. 89% rarely did not reveal the truth to patients regarding their diagnosis and stage of disease. Interestingly, in this study, the doctors claimed to believe that patients had the right to be aware of their illness; but they argued of lacking any training in communication skills (Table 3-1).

Table 3-1 Studies on health professionals' attitudes on disclosing the truth (adapted from Mystakidou et al., 2005)

PHYSICIANS

Authors, year published	n	Always or almost always	Sometimes	Rarely or never	Patients' right to information disclosure	Inadequate training on communication skills	Information to the relatives
(Manos and Christakis, 1980)	71	7%	20%	73% 95%	-	60%	-
(Dossios et al., 1986)	120	13%	-	88%	74%	100%	100%
(Mystakidou et al., 1996)	228	11%	78%	11%	-	61%	83%
(Mystakidou et al., 1999)	1280	22% diagnosis 28% prognosis	-	78%	-	78%	76% diagnosis 56% prognosis

NURSES

Authors, year published	n	Always or almost always	Sometimes	Rarely or never	Patients' right to information disclosure	Inadequate training on communication skills	Information to the relatives
(Georgaki et al., 2002)	148	19%	-	81%	72%	66%	72%
(Mystakidou et al., 2002a)	210	15.2%	-	85%	70%	-	60%

During the 1990s, two cross-sectional surveys by Mystakidou et al. (1996, 1999) explored the practices of sharing information about diagnosis and prognosis with cancer patients amongst oncologists and general doctors. The first survey (Mystakidou et al., 1996) conducted in a sample of 228 oncologists and radiotherapists during 1993-1994 revealed a change in disclosing the diagnosis of cancer. Although only 11% chose to disclose the truth, the majority (78%) considered breaking the bad news depending on whether that would be harmful for patients. The choice of communicating the truth to the patients was

dependent more on the doctor's assessment of the patients' personality (74%) and the anticipated reaction of the individual patient, rather than upon the physicians' personal values and preconceptions. However, it was unclear what the authors meant by the terms 'personal values' and 'preconceptions'. Although a change begun to show in doctors' willingness to communicate openly bad news, it still remained quite low (22-28%) and depended on their own judgement and assessment of the patient capacity to accept the reality. As in the previous study, doctors informed the patients' family most of the times (83%) and in advance of their communication with patients. Contradictory evidence came from the second cross-sectional survey, conducted three years later, including a bigger sample of physicians from both oncology and general hospitals (Mystakidou et al., 1999). According to the study findings, the majority of the physicians (78%) chose never or rarely to disclose information about diagnosis and prognosis, and only 22% shared the information openly almost always. However, in this study, 43% of the physicians reported that they informed patients about the palliative nature of treatment. It would perhaps be useful to know the different responses between doctors in general and oncology hospitals as this might have influenced the different outcomes, comparing to the previous study of Mystakidou et al. (1996). Also, diagnosis and prognosis have been grouped together; so it is unclear if doctors would deal information differently, at different stages of the disease.

It seems that similar to doctors, nurses preferred to discuss issues of disclosure and care with families instead of patients. A postal survey conducted by Georgaki et al. (2002) attempted to explore nurses' attitudes towards truthful communication. They recruited 148 nurses (74% response rate) from the main oncology hospitals of Athens who completed a self administered questionnaire. Although 71% argued that truthful communication was essential to a therapeutic relationship, 89% preferred that the whole truth to be disclosed to relatives, instead of patients, supporting that relatives' familiarity with patients might prove more positive for coping with the diagnosis. Half of the nurses (51%) believed that a fully informed patient might develop feelings of despair,

disappointment and isolation, particularly in the terminal phase. Finally, 80% supported that disclosing the truth to the patient was not part of their role, but doctors' responsibility. Indeed only 19% chose to disclose the prognosis to patients. Those results were independent to gender, age, education and experience. Similar results were reported by another study by Mystakidou et al (2002a), regarding nurses' attitudes towards quality of life and treatment choices for terminally ill patients. The sample consisted of nurses from Oncology hospitals or oncology clinics within general hospitals. Out of the 210 nurses, who took part in the study, only 15% got involved in the revealing of patients' diagnosis and a 20% of the prognosis. On the other hand, nearly 60% discussed information regarding diagnosis and prognosis with patients' families. In this study, 51% believed that it was ethically acceptable to inform families with the details of illness and care, when patients refused to know the details of their illness. Both nurses and doctors, in all the previous studies, underlined their inadequate training in communication skills and breaking bad news, which might have affected their attitude. Nevertheless, samples were conveniently chosen, and the numbers were not discussed against the actual populations under study; therefore representativeness of the oncology nurses and physicians might not have been secured.

Spain awareness studies have also discussed the reluctance of health care professionals to provide full disclosure. This trend seems to persist over time (Fainsinger et al., 2003). Two main barriers to honest communication were found: family resistance, hence tolerating the conspiracy of silence imposed by relatives and the uncomfortable feeling/ lack of training in breaking bad news (Bruera et al., 2000). In Italy, awareness studies published during 1994-2009 showed a similar persistent trend of non disclosure or partial disclosure (Pronzato et al., 1994, Caruso et al., 2000, Corli et al., 2009). Again, choices of non disclosure were reported to be affected by families' wishes and not patients' preferences (Locatelli and Piselli, 2010). However, health professionals' preferences appear to shift towards open communication and recent reports suggest that patients are

more informed and less passive about their diagnosis and decisions about their care compared to the past (Annunziata et al., 1996, Lucchiari et al., 2010).

Public and patients' views on communication

Public and patients' engagement in communication and information was another theme revealed by the review. Seven studies were identified, two of the general public view and four of patients with cancer and or terminal illness (Table 3-2). The earliest study identified, was a cross-sectional survey conducted by Sarfakis and Papachristodoulou (1972) during the 1970s with a sample of the Greek population. The authors reported that 72% of the sample (2000 participants) did not want to know the truth, fearing the possibility of a cancer diagnosis and the consequence of dying of it.

A decade later, Lavrentiadis et al. (1988) conducted an interview study with 116 cancer patients from Thessaloniki (north Greece), with the aim to investigate patients' knowledge and wishes to be informed about their diagnosis and prognosis. Stage of disease varied from initial stages to terminal illness and the mean age was 50.8 (SD 15.3). Although only 15% were informed about their diagnosis and even less of their prognosis (4.3%), a shift towards patients' wish to be informed was reported. Nearly 50% wished to know their cancer diagnosis and even more (69%) wished to know their prognosis, suggesting that the outcome of the disease might be even more crucial than the actual disease. However, more than 50% were suspected their diagnosis and/or prognosis. They said they expected their therapy just to help whilst 27% only expected cure. It is noteworthy, that 49% of the participants disagreed with the policy of withholding the truth from patients. The authors- psychiatrists- also, explored the coping strategies of those patients. They found that suppression (37%) and passive acceptance (30%) were the most common strategies employed by the patients.

3. Background II: End-of-life care culture in Health Care in Greece

Table 3-2: Studies on public and patients' wishes for communication/awareness of diagnosis and prognosis

PUBLIC

Authors, year published	N	Wishes to know the diagnosis and/or prognosis			Aware of diagnosis and/or prognosis		
		yes	no	depends/ unsure	yes	no	suspects
(Sarfakis and Papachristodoulou, 1972)	2000	30%	71%	-	-	-	-
(Dalla-Vorgia et al., 1992)	500	33%	34%	32%	-	-	-

PATIENTS

Authors, year published	N	Wishes to know the diagnosis and/or prognosis			Aware of diagnosis and/or prognosis		
		yes	no	depends/ unsure	yes	no	suspects
(Lavrentiadis et al., 1988)	116	49% 69%	34% 22%	17% 10%	15% 4%	32% 31%	53% diagnosis 65% prognosis
(Papadimitriou et al., 1998)	120	-	-	-	78% diagnosis	32%	-
(Iconomou et al., 2001)	100	40% 50%	42% 31%	18% diagnosis 19% prognosis	37%	59%	-
(Mystakidou et al., 2004)	120	50%	30%	20%	-	-	56% prognosis

Dalla-Vorgia et al. (1992) explored public attitudes towards truth telling of prognosis. They conducted a cross-sectional, on a convenient sample of 500 people (255 women and 245 men), from both urban (Athens) and rural areas (south of Greece). Preferences seem to vary depending on age, education, family status, occupation, place of residence and religion. Among all those studied 33.4% agreed in disclosing the truth when in the terminal stage, whilst 44% agreed with disclosing the truth in the case of maximum 5 years prognosis of survival. Younger people and those living in urban areas had a higher preference in disclosure of prognosis, whilst older people (61%), living in rural areas (65%) and with low education (68%) were supportive of withholding the truth. The answer for doctors (60%) and people with higher education (41.6%) was 'it depends'. Religiousness (40%) was related with a negative attitude towards disclosing prognosis, as well as experience with the loss of a loved one -particularly the mother-(53%). Those results should be interpreted with consciousness as the samples conveniently recruited and only a small, rural area included comparing to the capital. Also, no information is given about the analysis method; it is unclear whether they adjusted for the factors they

tested and what the interplay of those factors might be. It would have been useful to add a free space in the questionnaire for people to explain the reasoning of their choices, in order to understand those attitudes deeper.

The next study identified was conducted six years later by Papadimitriou et al. (1998). The study involved 120 patients from the South Western regions of Greece split in two groups (informed and none informed). The researchers aimed to capture the psychological responses of cancer patients to diagnosis and prognosis disclosure, and their wish of being informed. They applied a screening questionnaire of psychological responses, an interview and also did some observation of the breaking-bad news sessions. The authors identified age and education as factors influencing patients' desire for disclosure. They found that older and less educated patients had preferred not to confront their diagnosis and prognosis at all stages, whereas younger and more educated people were keen for full information disclosure. However, they reported that well-informed patients were 63% more anxious and depressed than those who had no information at all. Several methodological issues may have influenced this study's results. The questionnaire and the interview process were not described, and thus we do not know how the researchers measured participants' emotional responses. Also, the authors claimed that the questionnaire was adapted to each case according to the patient's profile; hence its reliability and validity cannot be applied. Patients were informed about their diagnosis from different health professionals each time, and no information provided as to what the breaking-news session involved, although the researchers mention that they observed such sessions. Additionally, it is not reported at which stage of the disease patients were offered this information, and it is unknown how they performed later in the course of illness, anxiety and depression might be the immediate feelings but may not necessarily lead to poor coping with the illness.

Iconomou et al. (2001), a multidisciplinary team, conducted an interview study with 100 cancer outpatients, recruited from the oncology clinic of the university hospital of Patras

(3rd biggest city of Greece, Southwest region). Even though, the majority of the patients (59%) were not aware of their diagnosis, comparing to the previous study (Lavrentiadis et al., 1988) an increase of informed patients (37%) was reported. However, the authors did not explore the possibility of patients being suspected of the truth. Patient's awareness was associated with their type of cancer, age and educational level. Patients at advance stage of disease expressed a greater need for information overall than those at earlier stages. In this study, patients were asked to score their need of information in relation to diagnosis prognosis, treatment and symptom control using a four item Likert scale, from 'not at all' to 'very much'. Patients scored higher in the wish of knowing the prognosis (50%) than diagnosis (40%), agreed with the pattern found in the study of Lavrentiadis et al (1988).

Findings from a cross-sectional survey conducted three years later- as part of a development of a quality of life instrument suggested a shift in patients' desire to be informed and also to take part in the treatment decisions (Mystakidou et al., 2004). The researchers - members of some of the first palliative care teams in Greece- challenged the argument that Greek cancer patients might not be able to face the reality of their prognosis. The sample of the study consisted of 120 terminally ill cancer patients (mean age 61), who received only palliative care and were recruited exclusively from their unit. 56% of the patients stated that they did not fear death despite the fact that the truth of their diagnosis and prognosis kept hidden. However, the study conducted in a palliative care unit, instead of a curative centre and that may have influenced patients' attitudes comparing to others who received care in other settings. Additionally, 50% reported that they would wish to choose their treatment, whereas 47% believed that they had chosen their treatment. The fact that 47% of participants said that, raises the following question: What did patients mean by wishing to choose if they felt that they had already chosen, despite the fact that they were not informed about their diagnosis and prognosis? How

choice is perceived among Greek patients and if it is connected with autonomy should be investigated before we suggest changes in approaches and models of care.

Studies on the healthy population (Sarfakis and Papachristodoulou, 1972, Dalla-Vorgia et al., 1992) showed less preference in disclosing the truth; yet, they are quite old to be able to compare with the recent studies (Iconomou et al., 2001, Mystakidou et al., 2004). Nevertheless, when comparing with the oldest study on the patient population (Lavrentiadis et al., 1988), it shows clearly that patients wished to know the truth about their diagnosis and even prognosis more than the public. Maybe, responses to hypothetical questions do not necessarily represent the views of people when they experience the problem, and this should be considered when designing studies.

Since 2004, no other studies were identified exploring patients' wishes, preferences and choices with regards to communication. It is possible, that patients' attitudes and preferences towards truthful communication might have shifted ever since.

Spanish studies reported a trend of patient reluctance towards information disclosure with regards to diagnosis and prognosis, similar to Greece. Stiefel and Senn (1992) found that patients avoided confirming cancer diagnosis and physicians did not explain the exact nature of the illness. Nunez Olarte (1994) on 92 terminally ill patients revealed that 68% of the participants had not been informed about their diagnosis and that 42% of the uninformed patients did not want to receive additional information even though they were suspecting the true nature of their disease. However, more recently, Nunez Olarte and Guinen (2001) found that younger patients were more likely to want an open discussion, highlighting the dynamic character of communicating the truth. On the other hand, studies with healthy populations show that preferences shift towards open disclosure (Osuna et al., 1998, Fernandez Suarez et al., 2002).

Family involvement in communication

The institution of the family is central within the context of health care in Greece (Iconomou et al., 2001). According to the Greek view, the patient belongs to the family and decisions as well as care responsibilities are family issues (Ioannidou E, 2008). This may also influence communication in relation to diagnosis and prognosis. The family's wishes rather than patient's preferences appear to be immensely influential when decisions are made (Mystakidou et al., 2004). Mystakidou et al (2002b), in cross-sectional survey conducted with 146 family members of terminally ill patients (age range was 19-80, mean 48, s.d 15), explored families' attitudes and preferences towards truthful communication with regards to diagnosis, prognosis, treatment choices and side effects. The survey was drawn using stratified random sampling, based upon the level of first degree relatedness. However, the recruitment was restricted to the specific palliative care unit the authors work and were relatives of patients who did not receive active treatment. The scores of item of the questionnaire that examined of families preferences with regards to communication of diagnosis, prognosis, treatment choices and side effects are presented in Table 3-3. Only 23% believed that the patient should be informed about diagnosis or prognosis (23%), whereas more than 50% would consider it sometimes. Interestingly, even though families appeared quite reluctant for patients to be informed about diagnosis and prognosis, 71% supported the right of the patient to be informed about possible treatment choices. However, half of them would not agree to communicate issues of effectiveness, complication and side effects. This raises the question; how do they perceive the notion of the informed patient about treatment choices, if the truth of effectiveness and side effects is not disclosed and what are the clinical implications for this attitude?

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Table 3-3: Families attitudes towards truthful communication with patients (adapted from Mystakidou et al., 2002b)

Questionnaire item	Answer options					
	'yes'		'sometimes'		'no'	
	%	n	%	n	%	n
1) Do you believe that the patient should be fully informed						
<i>a) about the diagnosis?</i>	23%	34	56%	82	21%	30
<i>b) about the prognosis of the disease?</i>	23%	34	51%	74	26%	38
2) Do you agree the patient to be informed						
<i>a) about the possible treatment choices?</i>	71%	104	24%	35	5%	7
<i>b) about the percentage of effectiveness?</i>	51%	74	37%	54	12%	18
<i>c) about complications or the side-effects of treatment?</i>	53%	77	33%	48	15%	21

Similar observations have been reported in Spain, where the majority of Spanish families (61-73%) are opposed to disclosure (Nunez Olarte and Guillen, 2001). In the same vein, in Italy, serious prognosis is often hidden from the patient but not from the family (Surbone, 1993). In Italy, families' preferences were reported to become obstacles in the doctor-patient communication and full disclosure of diagnosis and prognosis (Grassi et al., 2000, Giannini et al., 2003). Perhaps this is related to the fact that, in south European countries, family bonds remain particularly strong, and the families assume responsibility for decision-making on the patient's behalf.

It should be noted that the code of medical deontology in Greece (code of medical practice and ethics) did not include any regulation with regards the information disclosure to patients or the family, up until 2005. Since then, Hellenic Ministry of Health revised the code, regulating a series of clinical ethics issues, including the matter of diagnosis disclosure. It is indicative that the provisional draft Code of Medical practice and Ethics- as suggested by the Greek medical association- suggested in close 14 paragraph three that the doctor has general duties of truth towards the patient, but if he considers that the disease or its evolution is particularly painful or unfavourable, may allow partial disclosure or hide the truth from the patient. Conversely, the physician must inform the patient's family (Ministry of Health, 2005). However, the final text of the code of the

Ministry of Health (2005) did not allow such exemptions information, but only for those who do not have the capacity to consent. It clearly stipulates that doctors should disclose the truth of the disease, exclusively to the patient. Also, according to close twelve; the doctor is not allowed to perform any medical actions without the consent of the patient who should be fully informed. Even though, the code applies since 2005, health professionals continue publishing their objections with regards to the code (Ioannidou E, 2008), or their interpretations and implications for practice until now (Obessi, 2011).

3.3.2 End-of-life decision-making and treatment choices

Evidence looking at treatment options and end of life decision-making was identified in three studies, conducted by one of the palliative care teams in Athens (Table 3-4). However, all three studies were conducted at least ten years ago; thus any conclusions within the current context of care should be cautiously considered.

Table 3-4: Studies on end of life decision-making and treatment choices

First author, year published	Sample	Chemotherapy /radiotherapy	Enteral/ parenteral feeding	ICU admission	Psychosocial care	Place of care and death
(Mystakidou et al., 1999)	1280 physicians (85%)	-	-	16%	44% psychological care 40% social care	-
(Mystakidou et al., 2002a)	210 nurses (70%)	10%	8%	23%	63% psychosocial care 12 % all	90% home
(Mystakidou et al., 2002b)	146 family carers (100%)	-	-	30%	44% psychological care 78% social care	Place of care 57% home 20% hospital Place of death 41% home 34% hospital

A postal survey by Mystakidou et al. (1999) was the first study identified looking at physicians' attitudes and preferences in patient care. Physicians (446 internists, 640 oncologists and 213 anaesthetists) from across regions responded to a questionnaire in relation to information disclosure and factors influencing their decisions of treatment. According to their results, expected effectiveness was coming first in the hierarchy for a majority of physicians (61%) whilst 28% chose as expected survival as first. Second more important was the expected survival (41%). Quality of life was scored fourth (41%)

whereas consequences for the patient's sexuality seem it was their least concern (63%). Definitions or descriptions of those factors set from the outset were not given. In addition, there was no explanation given for the selection of those factors by the researchers. Although, physicians showed that they considered patient's quality of life when making decisions of care, it is not clear what they meant by that. For example, it seems they were not concerned about patients' sexuality, whilst for some patients it might have been a significant parameter of the quality of their life. The survey sample was conveniently chosen but also representing mostly male physicians (70%). The items of the questionnaire were quite general and vague, hence not allowing much interpretation over the participants' choices.

Another study by Mystakidou et al (2002a) examined nurses' attitudes towards quality of life and treatment choices in terminally ill patients. 210 nurses (70% response rate) from oncology and general hospital across Athens responded to a postal survey. The majority of the nurses (93%) would not choose interventions to extend life where quality of life would not be guaranteed. More specifically, 92% disagreed with enteral or parenteral feeding in terminally ill patients. Additionally, 90.5 % disapproved the choice of radiotherapy and chemotherapy with a possibility of worsening symptoms, whereas 23% agreed with an ICU admission, with the aim of life extension. Lastly, most of the nurses (89.5%) supported home as the preferred place of care and death for the patients. With regards to psychosocial care, 62% of nurses supported that this role belongs to specialist psychologists; whereas and only 11% supported that all health professionals and families should provide psychological care.

During the same period, families' perceptions and choices in patient management were explored, whilst developing a measurement tool (Mystakidou et al., 2002b). 146 family carers of terminally ill patients, approached in the outpatient service of a unit of pain and symptom relief, were recruited using stratified random sampling based upon the first-degree of relatedness. The authors measured families' attitudes in three areas:

information disclosure; treatment choice and place of care and death. The majority of participants were females (39 men and 107 women), covering an age range of 30-98 (mean 48, s.d. 15). Most of the families (57%) preferred their loved ones to be cared at home, but with the provision of the appropriate care, suggesting home as the most appropriate place of care at the end of life. However, fewer favoured home as the place of death (41%), although still more than hospital (34%). It should be mentioned that there was no any other available option offered in the questionnaire. It would be interesting to explore if families would consider other options and if offered whether the percentages for home/ hospital options would be influenced. It is also unknown the factors influencing families preferences and what the rest 25% would consider who opted for the 'sometimes' answer. With regards to psychosocial care, 76% considered necessary the involvement of all the health care team besides their doctor. Families showed a preference towards social care (81%) comparing to psychology (44%) and no available explanations were suggested. Worth noticing, a third of the carers (30%) would choose for the patient to enter ICU in order to prolong life within the final stage.

Mystakidou et al (2002b) tried also to explore families' reasoning behind choices of medical treatment offering options among seven factors (Table 3-5). Families suggested that when ranked those factors. Expectancy of survival was found to be the most significant factor (28%) whilst the second principal concern was the long-term quality of life. Treatment effectiveness scored third (16%) whilst patient choice was ranked 4th (12%). Short -term quality of life (5.5%), possible side effects and complications (3%) took least priority. It is though difficult to interpret those results as the items have not been presented and it is unclear what those factors meant. For example, expectance of survival was considered in relation to the proposed treatment or to the prognosis of the patient (i.e. short prognosis, hence no point of trying a treatment). Also, given that participants were family members of terminally ill patients, long-term quality of life might not be applicable. It would help if authors defined those parameters. Interestingly this

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study showed that if a longer term quality of life was secured, most families would not give priority to the patient's choice (ranked 4th) and the side effects of the treatment. Again, if families were aware of the imminence of death of their loved ones, why did they choose longer term quality of life over complications and side effects of treatment? Anyhow, the results might not be representative to other settings as patients of this unit received only palliative care and not active treatment; not necessarily the case for the rest of Greece. In addition, the majority of the sample was women which might reflect a cultural trend for Greece.

Table 3-5: Ranking of treatment choices (adapted from Mystakidou et al., 2002b)

Choices	Expected survival	Expected Effectiveness	Complications/ side-effects	Consequences in sexuality	Patient's Choice	Short-term QoL	Long-term QoL
1st	41 (28%)	24(16%)	4 (3%)	0	18(12%)	8 (5.5%)	27(19%)
2nd	20 (14%)	41 (28%)	5 (3%)	0	11(8%)	20(14%)	27(19%)
3rd	20 (14%)	27(19%)	17(12%)	0	18(12%)	12 (8%)	28 (19%)
4th	23 (16%)	12 (8%)	26(18%)	4 (3%)	17(12%)	31 (21%)	11(8%)
5th	5 (3%)	17(12%)	30 (21%)	2 (1%)	24(16%)	28(19%)	17(12%)
6th	12 (8%)	2 (1%)	34 (23%)	26(18%)	28(19%)	14 (10%)	7 (5%)
7th	3 (2%)	0	6 (4%)	92 (63%)	8 (6%)	11 (8%)	4 (3%)

According to these studies, physicians considered the effectiveness of treatment (61%) when making decisions whilst nurses appeared to give higher priority to quality of life as more than 90% would not consider treatments which would compromise patients' quality of life. Somewhat contradictory, nurses (23%) would support more than doctors (16%) an ICU admission at the final stage to prolong life. It would be interesting to explore this attitude, given that even more families (30%) would choose this. Would they make such a choice in support of families' wishes or based on their views of patients' best interest or perhaps their own needs? Moreover, families appeared to value psychosocial care more than nurses and physicians. An interesting detail is that families showed a preference over social care services (78%) comparing to nurses and doctors who showed preferences to psychology care (63%- 44%). Exploring those preferences and in relation to the available services, would help the planning of palliative care services in Greece.

The Spanish literature in relation to place of death revealed that the percentages of the public who would wish to die at home were higher than those who die at home (Ramon et al., 2006). However, a recent survey showed that 50% of the population would choose an alternative setting for terminally ill patients (CIS, 2009). In other studies, although outdated, health care professionals seem to agree that home is the ideal place of death (Porta et al., 1997, Osuna et al., 1998). In Greece, there are no studies exploring healthy population/ patients and physicians preferences in place of care at the end of life and place of death.

Another issue related to treatment choices, was found to be pain management and consciousness. In a survey of 1200 physicians, it was found that 42% were reluctant to prescribe opioids for cancer pain (Mystakidou et al., 1998). Physical dependence and addiction were the principal concerns (30%). Many participants (20%) believed that analgesics should be administered as needed; while most of them (80%) felt that their education in cancer pain management was insufficient. Nonetheless, in a much later survey by Parpa et al. (2006), more than half of the physicians (57%) reported that they would choose sedation for symptom relief at the end of life.

The need for pain relief has led health professionals to sedate terminally ill patients in Spain (Nunez Olarte and Guillen, 2001). However, the need to sedate for reasons other than the management of purely physical symptoms, such as family distress, is a common occurrence in palliative care in Spain (Nunez Olarte and Guillen, 2001). Psychological/existential distress was associated with a peculiar cultural way of coping with terminal illness, where isolation (chosen by the patient) together with denial and rejection of diagnosis disclosure are prevalent. In a similar study between terminally ill patients of Spain and Canada, somnolence and confusion were not considered as pertinent issues for a large percentage of Spanish families and patients, whilst the decrease in the patient's capability to be autonomous due to sedation was resented in the Canadian environment (Fainsinger et al., 2003). Results reporting the occurrence of sedation for

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symptom management in studies conducted in Italy, a country with similar catholic tradition to Spain, might lead to similar interpretation (Ventafridda et al., 1990, Peruselli et al., 1999). In the study of Persuelli et al (1999), the wide variation in the frequency of sedation among palliative care centres may indicate the preferences of the health professionals and families rather than the patients' wishes or needs.

3.3.3 Euthanasia

The medical Greek literature appears to be concerned with the issue of euthanasia since the 90s. Euthanasia has been approached from a philosophical point of view exploring the moral debates around it (Gika, 1998, Koutselinis, 2000, Katsimigas et al., 2007); the legal point (Voultsos et al., 2010), and the historical point of view (Mystakidou et al., 2005). Five studies were identified which explored the views of the public, of health professionals and carers of terminally ill patients (Table 3-6).

Table 3-6: Studies on health professionals, public and carers' views on euthanasia and other end of life decisions

Authors, year published	Sample	Euthanasia	Assisted suicide	Withhold treatment	Withdraw treatment	Terminal sedation	Legalisation	Right of self determination
(Vidalis et al., 1998)	417 (83.4%) doctors 46 nurses 21 students/ nurses 120 public 230	27% terminally ill 33% doctors 22% students/ nurses 45% public	-	45% (support with mechanical devices)	-	-	42% terminally ill 32% doctors 20% nurses 45% public	56% overall 71% for those with mental capacity
(Mystakidou et al., 1999)	1280 (85%) 446 internists 213 anaesthetists 640 oncologists	46%	-	84% (mechanical ventilation in ICU)	-	-	-	-
(Liakopoulos et al., 2010)	210 nurses (84.8%)	35%	16%	43% (passive euthanasia)			-	51%
(Parpa et al., 2006)	314 (32%) 141 doctors 173 public	44% 40%	2% 8%	42% 25%	11% 5%	57%	48% 41.5%	44% 40%
(Parpa et al., 2010)	925 (46%) 215 doctors 250 nurses 218 relatives 246 public	 40% 27.5% 42% 42%	 2% 3.6% 0.9% 6.5%	 5 % 8% 3% 8%	 9.3% 7.6% 2% 7%	 - 	 47% 45% 49% 53%	 -

Vidalis et al. (1998) conducted a survey in order to examine the attitudes of the public and health professionals towards euthanasia in Greece. The context within which euthanasia

would be considered was set from the outset. Participants were asked to support if they would be in favour of euthanasia for a patient when s/he is suffering from unbearable pain, or terminal illness or incurable mental disease or physically handicapped. The option of not considering euthanasia at all was also given. A convenient sample of 417 subjects (83.4% response rate) replied to the questionnaire. The participants of the survey were 45% health professionals (11% doctors, 5% nurses and 29% student nurses) and 55% public. Nearly 27% of responders would consider it for terminally ill patients or patient with uncontrolled pain (13%), whilst 43% were against life extension with mechanical devices. Public was more in favour of legalising euthanasia (45%) comparing to doctors (32%) and nurses (20%). The researchers- a psychiatric team from Thessaloniki- tried also to explore the views of public and health professionals with regards to potential factors that would lead patients to ask for euthanasia. The main putative risk factors for suicidal ideation and desire for death were: a) pain (66.2%), b) despair (60.2%), c) depression (9.7%) and d) psychopathology (38.6%). Problems on the design of this study may have strongly affected its validity and reliability. The sample consisted mainly of female (84%) subjects and 29 % of student nurses. It would also be wise not to consider the views of student nurses as similar to the register nurses since their judgements would be restricted from the experience of clinical reality. Also, the results were not representative across age groups since 82% belonged to the group of 20-29years old. Another concern is that the general public group consisted of people working at the administration of clinical settings and hence not representing the general public. The factors associated with the desire of hasten death and euthanasia was set from the outset which might have introduced systemic biases. Moreover, the extended response time to twelve months may have introduced bias to the findings.

Greek physicians appeared to believe that euthanasia could be an option for dying patients even though the Hellenic Medical Association had repeatedly declared its opposition to euthanasia and for any reason (Karanis, 1994). In a survey looking at aspects of quality of

life by Mystakidou et al. (Mystakidou et al., 1999) 46% of a sample of Greek physicians (1280 participants) argued that they would consider euthanasia as an option and only 16% of them would choose the intensive care unit for a patient in the terminal stage.

In 2010, one more cross-sectional survey was published by Liakopoulos et al. (2010), exploring nurses' attitudes towards euthanasia. 212 nurses from four general hospitals in Athens took part in the survey. The sample consisted mostly of women (94%); their age ranged from 20-45 (mean age 33). They explored agreement or not with euthanasia, physician assisted suicide, and self right on life and death. Only 35% supported euthanasia, whereas the support for physician assisted suicide was even smaller (16%). Nurses were more supportive towards passive euthanasia (42.5%) in cases of terminal illness and patient suffering. However, the views on a person's self right to choose life and death seem to be divided (51% positive). It should be mentioned that the authors did not make clear how they defined passive euthanasia and also if there would be any differences between withholding or withdrawing treatment. Factors influencing nurses' views were reported to be religiosity (against euthanasia), and age for passive euthanasia (age groups of 20-25 and 41-45 against euthanasia). No information about the tool was presented which forbids any conclusions regarding its validity and reliability.

Within the last decade, a palliative care team in Athens conducted two comparative surveys looking at attitudes on euthanasia more systematically (Parpa et al., 2006, 2010). The first cross-sectional survey included 141 physicians and 173 lay people (Parpa et al., 2006) and no statistical significant differences, were found between the two groups. Most physicians (81%) and lay people (87%) had never received requests for euthanasia. Discussion on physician assisted suicide had been held by 15% of physicians and 27% of lay people with regards to terminally ill patients with uncontrolled symptoms. Most of the physicians (56%) and lay people (60%) would never agree with euthanasia for any reason. Withholding or withdrawing treatment was mostly viewed as a decision of securing quality of life and not of hastening death. Only 11% of physicians and 5% of the

lay people reported that death had occurred after a decision made to withdraw a life-sustaining treatment with the intention to hasten a patient's death. Terminal sedation was administered by almost 57% of the physicians. The researchers also found that physicians withheld or withdrew life sustaining treatment more than lay people. Nevertheless, despite their differences, both the corresponding percentages for all willing respondents were relatively low. Also, despite the public being more supportive to physician assisted suicide, both groups displayed a negative attitude (2% and 8% respectively). Most physicians (76.2%) had discussed patient assisted suicide following the patient's request. With regards to self determination of patients in relation to requests of hastening death, 56 % of physicians and 60% of the public would not agree and allow it.

The second survey by the same team (Parpa et al., 2010), expanded to nurses (n=250) and relatives of terminally ill patients (n=218); apart from physicians (n=215) and lay people (n=246) across Greece. Physicians mean age was 39.76, whilst they were mostly men (133). Nurses and lay people were younger (mean age 34), single and female (182/120 respectively). Terminally ill relatives' mean age was 44.75 whilst most doctors and relatives were married (136/133 respectively). Although the majority of physicians revealed that they had not a direct request on euthanasia, many more (20%) had received such requests comparing to the rest of the groups (nurses 3.6%, relatives 11%, and public 6%) but had not complied with those requests. Given that euthanasia in all forms is illegal in Greece, it is understandable that health professionals are not practising it (Voultsos et al., 2010). The majority of participants did not support euthanasia. The responses of participants were correlated with their religiosity. 40% of the physicians, 27.5% of nurses and 42% of relatives and public declared that they believed in the church's teachings. As mentioned earlier, the Orthodox Church opposes euthanasia; for Christians, the decision regarding the moment of death belongs to God; since life is God's gift, euthanasia is considered a murder (see section 2.1 historical overview).

Perhaps a direct comparison between studies is risky as the terminology varied across the years and the concepts were not clearly defined. For example, the term passive euthanasia appears to represent withholding or withdrawing treatment in different studies. Also, it is not clear what clinical practices were defined within the different types of euthanasia and withholding/withdrawing treatment (e.g. support with mechanical devices; hydration; nutrition), which might have influenced the responses. For example in the first two studies (Vidalis et al., 1998, Mystakidou et al., 1999), a much higher response (45%/ 84%) was given to withholding/withdrawing sustainable treatment, because 'support with mechanical devices' was presented as a withholding treatment option. Nevertheless, this suggests clearly that the Greek health professionals and people were not supportive of such an option for terminally ill patients. Conversely, the studies by Parpa et al. (2006, 2010) showed much lower responses. It is unclear whether there has been a shift over time, or answers were reflecting the fact that clear distinctions between those terms were made; introducing separate items in their questionnaire for each of those. The study samples were relatively small. The response rates of the two comparative surveys were 32% and 46% respectively, and authors did not report if studies were sufficiently powered; leading to a disinclination of generalising the results. Most of the studies included populations of the two large cities Athens and Thessaloniki hence no conclusions could be drawn in relation to geographical areas and urban/ rural communities, it is compelling that the more than half of the subjects in all the relevant studies supported the right of self determination. This should be considered when exploring views towards patient autonomy. Lastly it should be noted that, in all studies, nurses were much less supportive of euthanasia comparing to doctors, carers and lay people. This attitude should be explored further. Lastly, no studies were identified exploring attitudes towards euthanasia of patients themselves. It would be interesting to explore if this reflects a view that such decisions should be made by doctors and families or the reluctance of disclosing prognosis to patients.

Health professionals in Italy and Spain seem to share the same attitude towards euthanasia. Grassi et al. (2000) who conducted a survey among 520 GPs in North Italy showed that only a minority of Italian GPs (15%) favoured euthanasia or assisted suicide, whereas a higher percentage agreed with the possibility of withholding treatment. Nunez Olarte and Gracia Guillen (2001) discussed similar findings for Spain. 72% of health professionals indicated that more attention to the quality of life and pain control would eliminate the need for euthanasia. Agreement with the practice of euthanasia was correlated with a) non-catholic religious affiliation b) inexperience in treating terminally ill patients and c) the emotional exhaustion due to working with terminally ill patients. However, It should be noted that acceptance of euthanasia in Spain has risen among the general public since 1995 (CIS, 2009). A European survey by Cohen et al. (Cohen et al., 2006), looking at public acceptance of euthanasia showed that Spain held an intermediate position within Europe (4.73 mean score), but Italy held one of the lowest percentages of euthanasia acceptance (3.86 mean score) Religiosity and tolerance was found to be the two most influential factors influencing views towards euthanasia. In the same study, Greece scored in between Spain and Italy, but closer to Spain (4.20 mean score).

3.4 Summary and conclusions

The findings of this review of the health care literature support the findings from a cultural perspective discussed in chapter 2. It suggests that Southern European countries share many similarities in the end-of-life care culture, but they also have some differences. Greek, Spanish and Italian families and health professionals are reluctant to inform patients about their diagnosis or prognosis, and they prefer to inform the families rather than the patients themselves. However, whilst Italy and Spain seem to agree on sedation measures for either symptom management or because of a family's distress, Greek physicians do not prefer it. Also, whilst Spanish and Italian physicians appear not to be supportive of Euthanasia, Greek health care professionals appear to be more open and consider it as an option for the terminally ill patients. Most of the Greek papers explore

families and health professionals' perspectives with regards to the care of advanced cancer patient, whilst Spain and Italy seem to have started focusing more on patients' views. Perhaps the development of palliative care in these two countries has enabled a more patient-centred care, whereas Greece still has remarkably limited palliative care provision.

On a methodological note, several issues can be raised based on the research design of the papers included in this literature review. Most of the studies- all the Greek ones- are surveys, cross-sectional studies, hence offering a view at a specific time point. Also, they may provide insight into attitudes and preferences but they cannot explore the possible meanings or discover factors influencing them deeper. Only some Greek studies describe inclusion and exclusion criteria for their samples and most of them are small, conveniently chosen and were recruited from local settings. Conceptual clarity for the terms 'terminally ill' or 'advanced cancer' patient do not exist. Thus, representation of the target population may not have been guaranteed, and generalisation of the findings may not be applicable to the whole country. Finally, no recent research evidence (up to 2005) was found in relation to end-of-life care culture, which leads to a concern when making concluding remarks for the 2012.

Qualitative, longitudinal studies need to take place as they can go deeper into meanings which may influence attitudes and behaviours; notions which may derive from cultures or even shape them. Qualitative, longitudinal studies are required because they can also identify changes of quality of life and patients' preferences over time. Moreover, qualitative, longitudinal studies may supply us with information about diverse pathways to death and an understanding of the nature of the terminal illness, as well as patients' and families' experience of it.

4. Aim and objectives

Aim

To discover the nature of care received by patients with advanced cancer in Greece and how they and their families experience the care and the illness over time

Objectives

1. To observe and explore the care patients with advanced cancer receive in Greece;
2. To understand how the decisions about care were made;
3. To explore patients and families' preferences and wishes for care;
4. To explore the experience of patients and their families of the care they receive;
5. To explore the interactions between health professionals, families and patients and understand how they are involved in patient care;
6. To explore health professionals' perceptions of their role, their attitudes towards end-of-life care and patient/family needs;
7. To explore what patients consider important in their everyday context;
8. To identify factors which patients with advanced cancer and their families perceive will help and support them through their illness trajectory;
9. To explore preferences and wishes at the end of life, including place of care and death;
10. To consider if and how each the above change over time.

5. Methods

5.1 Introduction

The purpose of this chapter is to present and discuss the methodological approach and procedures followed. The chapter also explains the theoretical framework within which the study was embedded and presents in detail the data collection and analysis methods utilised.

5.2 Theoretical framework

Fundamental to how research is conducted and how data are analysed and interpreted are the researcher's ontological/theoretical and epistemological positions. Ontology refers to theories of the nature of reality and its basic elements while epistemology refers to the nature and status of knowledge.

In order to achieve the aim and objectives of this study, an inductive qualitative research approach was chosen. This approach provides a deep understanding of social phenomena because it is concerned with the study of social life in real, naturally occurring settings (Hamilton, 1994). In inductive, qualitative research, the researchers study people's feelings, perceptions and actions in situations which are not experimentally contrived or controlled (Atkinson et al., 2001). For the present study, understanding the nature of care in context (health care in Greece) was critical.

The study is theoretically situated within social constructionism, as it considers that the dying process and patients' experiences of their illness and care are constructed over time by the patients themselves, their interactions with those involved in their care and the broader context in which these experiences are taking place (Seale, 1998). According to social constructionism, human beings do not discover knowledge so much as they construct or make it. Human beings invent concepts and models in order to make sense of their experiences, and they continually modify those constructions in the light of new

experiences. It is postulated that these interpretations are constructed within shared understandings and practices of a historical and socio-cultural background. For this reason, the context in which human behaviour occurs is crucial. A study of the experiences of care and illness of patients with advanced cancer and their families should not explore participants' perceptions and feelings in isolation, but in interaction with those involved in their care; taking into consideration the socio-cultural context and the health care setting where these are expressed and evolved over time.

People act within the context of a pre-existing social structure which is governed by a set of norms and rules (which inherently includes culture), and which are distinct from those of other social structures. Although social structures make social action possible, at the same time the social action creates those very structures (Giddens, 1984). Based on this argument, patients' actions, behaviours and choices could be influenced by the culture of the setting where they were cared for and the nature of care provided to them, their family environment, and the health professionals involved in their care. In turn, the nature of the care received by patients could be influenced by the illness itself and also by patients' preferences and wishes, as well as their families' involvement. Hence, social constructionism provides an appropriate theoretical framework for this study to explore and understand the experiences, behaviours, feelings, and attitudes of patients, families and health professionals, exploring the social structures and context of the health care setting within which all these are constructed.

In order to understand patients' experiences of their illness and care, but also the nature of care delivered to them, exploring if and how these change over time, I needed to follow patients throughout their illness trajectory. Creswell (2003) suggests that long investigative processes are necessary in order for the researcher to make sense of a social phenomenon by contrasting, comparing, replicating and classifying the object of study; a researcher needs to enter the informants' world and through ongoing interaction should seek their perspectives and meanings.

Everyday life is argued to consist of an ordering daily life, with various traditions, rituals, routines, activities that are taken for granted, in which people invest energy, effort and resources – cognitive and emotional (Giddens, 1984). According to social constructionism, a personality cannot be understood outside of the routines of day-to-day life. Routine is integral both to the continuity of the personality of the person as one moves along the path of daily life, and to institutions of society, which are such only through their continued reproduction (Silverstone, 1994).

Considering the everyday life of patients with advanced disease is crucial in order to understand their living experience of the illness and the care they received. Because the everyday life and needs of this group of patients may change dramatically during the last stages of life, it was important to follow patients until as close as possible to death (Seale, 1998). In this way, the study could reveal changes in patients' preferences, values and beliefs that might take place during their illness trajectory. Moreover, such study could describe the everyday life of patients while they deteriorate. Equally, I needed to understand the everyday life of the institutions involved (family-oncology hospital setting) and to explore the interactions that take place between the involved parties. This could be well achieved through immersion in patients' life for a long time and through observing, experiencing, describing, understanding and analysing the features of this social life as they occurred. Hence, a longitudinal study was required.

5.3 Epistemological framework

Analytical realism was employed as the epistemological framework to address the aims and objectives of the study. This framework shares the cognition that knowledge is based on assumptions and human constructions (Altheide and Johnson, 1998). It rejects the dichotomy of realism/constructivism as being incompatible with the nature of lived experience. Instead, analytical realism supports the view that the social world is an interpreted world; not a literal one, but one always constructed by the people and by the

researchers who study them (Willis, 2007). While the researcher's commitment is still to obtain people's perspectives on social reality, analytical realism recognises that most fields have multiple perspectives and voices. Yet, although there are many versions of reality, this does not necessarily exclude the possibility of shared themes. This way, analytical realism addresses the differences and commonalities in perspectives/experiences in the social world (Altheide and Johnson, 1998). Consequently, the researcher must faithfully report this multi-vocality and also show where his/her voice is located in relation to these voices. It is, therefore, appropriate to frame the present study within analytic realism. In this way, feelings, perceptions, thoughts, behaviours and actions of patients, health professionals and families could reflect the multi-vocality of the experience of care and illness.

5.4 Ethnography as the methodology

An ethnographic approach was chosen for the methodology of this study; as its real strength relies on a well established, systematic and in-depth observation-based approach to studying people's behaviour in everyday contexts and considers the culture(s) within the group.

Ethnography is defined as the study of people in naturally occurring settings or fields by methods of data collection that capture social meanings and ordinary activities. This involves the researcher participating directly in the setting if not also in activities, in order to collect data in a systematic manner without being imposed on them externally (Brewer, 2000). This methodology facilitates the exploration of aspects related to the person who experience social phenomena and interacts with others, as well as the parameters of a social structure which might influence those experiences and interactions (Polit and Beck, 2004, Hammersley, 2002).

Ethnography also presents a method to better understand the 'local world', i.e. the context in which social phenomena take place, such as family (micro-level), institutions,

communities or nations (macro-level) (Spradley, 1980, Savage, 1995, Wiseman, 2002). In my study, the local world where experiences of care and illness took place is an oncology hospital within the Greek national health care system, in particular two wards and a day care clinic. Within these, there are two communities that interact closely with the patients: the health professionals and the families which the patients belonged to.

More specifically, there are four reasons why ethnography is an appropriate methodological framework for the present study:

- It studies people's behaviour in everyday contexts rather than under unnatural or experimental conditions. Participants' views and experiences of illness and care cannot be seen outside of the context they occur;
- It considers the culture(s) within the group. A study of Greek patients with advanced cancer within a health care system that lacks established specialist palliative care (including hospices) needs to be approached by taking into consideration particular cultural parameters;
- It provides the platform in which human behaviour may be linked to the meaning that a situation has for a person (Bloor, 2001). Thus, ethnography may offer the framework where participants' views and meanings may be elicited and represented; it may take a form of explaining the meanings that participants ascribe to their experience, and the ways in which they make sense of the world (Ware et al., 1999);
- Data collection techniques within ethnography (e.g. participant observation and interviews) are flexible and may be unstructured to avoid pre-fixed assumptions that impose categories on what people say and do. Therefore, an opportunity may be given to clarify meanings participants attribute to their behaviour throughout the research process.

Whilst understanding the participants' viewpoints is a necessary condition for social knowledge it is not entirely sufficient. There are more than individual actions and interpretations that need to be known (Porter, 1995). Ethnography may facilitate the exploration of all aspects, such as settings and interventions, as it is concerned with the whole picture of a phenomenon (Polit and Beck, 2004). In this study, an ethnographic approach provides the opportunity to explore the culture of an oncology hospital within the Greek National Health System, the sub-cultures of the health professionals working in this setting and how these structures may influence and shape individual interactions. Moreover, patients' viewpoints could be explored in relation to the circumstances where they developed, in relation to formal procedures and informal interactions with people involved in their care, within the context of the particular hospital.

5.5 Setting

The study concerns patients with advanced cancer hence the setting selected is a public oncology hospital in Athens, Greece. Since there is no specialist palliative care in Greece, advanced cancer patients are nearly always cared for until their death in the oncology hospital where they are treated.

The hospital was selected for a variety of reasons. It is one of the biggest public oncology hospital in Athens (with 350 beds in 2005) attracting patients from all over Greece, due to its reputation and expertise. Nonetheless, the setting was chosen to be in Athens, for feasibility reasons. I live in Athens and proximity to the study site was very important, not only because of the length of fieldwork, but because I needed to be flexible with the time available. For example, when nurses called me to see a patient in the middle of the night, I had to be able to be there as soon as possible.

Initially, I selected one of the three medical wards (hereby called ward Mariza, which is not the real name), following recommendations from the hospital nurse director and a nurse academic colleague. Ward Mariza (33 beds in 2005) was the medical ward with the

highest death rate and the team was familiar with nursing research undertaken by MSc students.

Although initially fieldwork commenced in the ward Mariza, it later encompassed more areas of the patient's journey, as the patient experience was the central concern of the study. These included one more ward and day care clinic of the hospital (details in section 4.6 Entry into the field and in Chapter 5: Setting). In order to follow patients throughout their journey, I also conducted observation in some public places of the hospital, such as the canteen and the front yard. A private health centre, the emergency room of another hospital and patients' homes also became fieldwork sites at different time points, as they supplemented patients' experiences of their dying processes.

5.6 Entry into the field

5.6.1 Securing access

Formal procedures

In September 2005, I approached the hospital to gain access to the research site, after securing ethical approval from the King's College London Research Ethics Committee (see more in section 5.16.1 Ethics committees). The plan was to approach the formal gatekeepers at the hospital. Formal gatekeepers could seriously influence my entrée as I had not worked in that hospital before, and thus I was not known there. I envisaged that if I gained their support I would then apply for approval to the scientific committee. After being granted official permission, I would then approach the head nurses of wards and subsequently the nurses themselves in order to gain final access to the wards. Bryman (2004) supports that every field situation is different and initial luck in meeting good informants, being in the right place at the right time and striking the right note in relationships may be just as important as skill in approach. Brewer (2000) insists that ethnographic research requires skilful negotiation and renegotiation. Building

relationships with gatekeepers calls for patience and openness as does building relationships with other people who are likely to be beneficial informants in the field (Schensul et al., 1999).

The first formal gatekeepers I approached were the nurse director and the hospital's chief executive. Mulhall (2003) advises that the first steps of negotiating access in health care settings often involves approaching the chief executive, consultant, nurse director and others in positions of authority and power. My previous experience in clinical practice in Greece suggested I should be highly respectful of hierarchy; any actions I took which might be misinterpreted as challenging someone's authority would have direct consequences for access. The nurse director of the hospital where I used to work and the president of the National Nursing Association in Greece helped me to approach them.

In October 2005, I presented my study to the nurse director and the chief executive, providing them with a supporting letter from my supervisors at King's College London (Appendix 1) and hoping for their support and advice. Shensul et al. (1999) emphasizes that if gatekeepers understand the nature of the project, the reasons for the research, the ways in which it will benefit their institution, they can become valuable allies in the study. Otherwise, they may become suspicious of the project and find ways to interfere with its success. Thus, I gave the nurse director and the chief executive a copy of the proposal I planned to submit for ethical approval and discussed with them the nature and the aims of the study, as well as its possible benefits towards the improvement of care. They expressed interest and committed to helping.

Informal procedures

I was not sufficiently aware during the early stage of this process about the hidden issues around gaining access, such as power dynamics and bureaucracy and thus had not predicted the length and difficulty of this process. It took me four months to gain all approvals and start the study, from the time I first approached the nurse director to the

time I entered the first ward. Sarsby (1984) supports that no matter how sophisticated forward planning might have been, the researcher will find him/herself in unknown situations, which could not, have been predicted.

It was suggested by the nurse director and the hospital's chief executive that a shorter version of my application was required for the Scientific Committee. They made some amendments in terms of changing the terms 'terminally ill and 'prognoses' (see more in section 5.16.1 Ethics Committees). In addition, the nurse director offered to write a letter to the scientific committee expressing support of my application. Fetterman (1998) suggested, support of someone within the organisation who could act as a 'sponsor' to the researcher; someone who could vouch for me and the value of the research, was very significant.

A family friend who was a consultant in the hospital finally was able to open the closed doors for me. As Van Maanen and Kolb observed (1985), gaining access to most organisations involves more than strategic planning and hard work; it often requires dumb luck. My luck changed when he introduced me to the chair of the scientific committee, giving reassurance of my personality and professionalism. Soon after, I received the approval of the scientific committee.

5.6.2 Entry into ward Mariza

After two months of negotiations, I was able to approach the sister and nurses of the first ward. The nurse director had pointed me in the direction of the main general oncology ward of the hospital - ward Mariza (the largest ward in the hospital, with 33 beds and many patients dying in location). A nurse academic with prior research experience in that ward mediated the initial contact. A meeting was arranged with the sister of the ward and then the nurses whereupon I presented my study. I provided them with a copy of the ethical approval from the hospital scientific committee, the information sheet for health

professionals and the consent form (Appendix 2). A second appointment followed to clarify any questions and receive their written consent.

5.6.3 Entry into ward Rallou

After eight months of field work in this ward, I realised the need to expand to another ward – hereby called ward Rallou - if it was to follow the patients' trajectory fully. At first, some of the patients recruited to the study had been admitted a few times to ward Rallou while waiting for a bed in ward Mariza. Also, I had not found patients over the age of fifty in ward Mariza. After some discussions with staff members and the admissions office at the hospital, it was revealed that older and more socio-economically deprived patients were admitted to ward Rallou - a smaller ward with fewer beds (n=21) and poorer facilities. It was also explained to me that patients who were dying were often referred to ward Rallou while ward Mariza was used as a place for more active treatment. This was an 'unofficial' policy of the hospital which people were reluctant to explain. For these reasons, I decided to expand observations and recruitment to ward Rallou.

Since I had already been 'inside' the hospital for several months, I found it much easier to access ward Rallou. The sister of ward Mariza mediated by introducing me to the sister of this second ward. She presented me as

... a very nice girl, very sweet with patients and eager to help where she can. She comes almost every day so she will be useful to you as well'. (Sister of ward Mariza; field notes, morning shift)

An appointment was arranged for me to present my study to the sister of ward Rallou. After that, I followed a similar process to the ward Mariza; meeting with the nurses; provision of information sheets and consent forms, and then a meeting with the main consultant and his team allocated to that ward.

5.6.4 Entry into the day care clinic

The other place I felt the need to access was the day care clinic as it became apparent that patients' frequently used this service. I visited the day care clinic a few times after I introduced myself while escorting one of the participants in the study. The nurses of the clinic thought I was a private health assistant hired by the patient because I wore a white robe and had sat for the whole time next to the patient. The nurse who looked after the patient noticed that I was recording a discussion I had with the patient, and she asked me what I was doing. The patient explained on my behalf.

She is a researcher; she comes every time I am in the hospital and spends time with me... She cares about our experience and our feelings and what we are going through. (Sila, audio1033, day care clinic, morning shift, 1 month before death)

The nurse found this particularly interesting and expressed general interest in the research. When I explained that I was interested in nurses' views, she offered to take me to the ward sister. The next steps were similar to the process I followed for the other two wards I entered.

5.6.5 Immersion in the field

I spent the first two months of data collection working solely with nurses while emerging myself in the world of ward Mariza. This time was necessary in order to familiarise myself with the work of the ward, their routines, the ways in which the nurses related to patients, the way they shared duties with families and the dynamics with other health professionals. During that time, I followed a patient, who acted as a pilot case.

When I felt confident with my immersion in the field, I approached the key consultant who had patients on this ward. I followed a similar procedure as with the nurses; first I had a meeting with only him, then a second one with his team where I handed out the relevant

documents, and finally a third one to answer questions and receive their written consent. The fact that they had already seen me in the ward, participating in the everyday life and seen the nurses being extremely friendly with me, made them feel quite comfortable and less threatened by me. The approval of the hospital's scientific committee also encouraged their trust towards me and the project.

5.6.6 Maintaining access

Securing access was an ongoing activity. During the data collection period there had been several times where I needed to discuss and re-explain the study; most often when my role as a researcher was challenged (see also section 5.9 Role in the field). Encountering similar issues, Smith (1996) reported that she had to spend considerable time in describing her method (ethnography) and what it would entail in reality for the hospital before she was accepted. I needed to elaborate on ethnography and on my project with all the people I met in the hospital since they were not familiar with this type of research. Similarly to Kelly (2002), provision of a clear explanation of the aims and methods and discussion about concerns raised, was particularly important in order to gain and maintain people's trust.

Constant reassurance of confidentiality and anonymity were crucial in maintaining trust and access, especially when their participants' views were audio recorded. People might have suspicions about the researcher, perhaps seeing him/her as an instrument of top management. If they have these worries, they may go along with the research but, in fact, sabotage it, engaging in deception and misinformation. There were times participants were worried that what they said could get back to bosses or colleagues or health professionals and in the case of patients, back to families. They repeatedly asked for my confirmation of confidentiality.

5.7 Sampling

Purposive sampling was undertaken to capture as much diversity as possible amongst respondents with regard to the variables of most interest: age, gender, diagnosis, family status (Table 5-1). The criteria were determined after examining hospital statistics in relation to deaths over the past two years. According to hospital records, the majority of patients who died in the hospital between 2005 and 2006 were diagnosed with breast, colon, lung, stomach, and urinary cancers.

Table 5-1: Sampling matrix outlining purposive criteria and sample size

Characteristics	Purposive criteria	Number of participants
Gender	male	6
	female	7
Age	Age 30-40	2
	Age 40-50	2
	Age 50-60	3
	Age 60-70	3
	Age 70-80	3
		3
Diagnosis	Breast cancer	4
	Lung cancer	3
	Colon cancer	1
	other	5
Family status	Married/partnership	8
	Not married	2
	Divorced/separated/widow	3
	Had children involved in their care	4
Main carer	Spouse	4
	Child	4
	Parent	2
	Other	3
Survival from point of recruitment	3 weeks- 1 month	3
	1-3 months	6
	3-6 months	4

After the recruitment of the first five patients (based on estimated prognosis), the remainder of participants were recruited taking into account that I needed to cover all ages from 30s to 70s-80s. Also, I felt the need to keep a balance between female and male patients and to cover the main cancer diagnostic groups of lung, breast and colon. I also tried to maintain a variety in terms of supporting-family environment, ranging from patient with no close family to wider family being involved. Over the course of fieldwork, I realised that the role of the main carer within the family - such as being the spouse, the

child, the parent - could play a crucial role in decision-making. Hence I tried to take this aspect into account during sampling, to ensure diversity.

The patient sample in study consisted of 13 patients alongside 34 family members. They were selected according to the following inclusion and exclusion criteria:

Inclusion criteria

- male or female aged over 18 years
- Patients with advanced cancer
- Patients not estimated to survive beyond 12 months by nurses
- Patients able to communicate and fully coherent at study entry
- Patients' home within or close to Athens

Exclusion criteria

Patients deemed unfit by the clinician to participate due to medical condition (physically and/or mentally).

5.8 Access to participants: recruitment strategies

I recruited the first participants to the study from ward Mariza. I asked health professionals to suggest possible participants and then approached doctors, and nurses with the question 'could you suggest to me any patients for whom you would not be surprised if they died within the next six months?' The same approach had been used by other researchers for whom limited prognosis was a criterion for their sample with favourable results (Oliver et al., 2004, Brumley et al., 2007). However, doctors found it extremely uncomfortable to point out patients who fitted the criteria of a poor prognosis. Such an attitude reflected the culture of the oncology hospital as represented by the scientific committee and the nurse director during my first contacts. They affirmed the hospital did not consider any patient to be terminally ill and that life expectancy was not on their agendas as the attitude was '*to fight until the very end*'. Nevertheless, after some

weeks they started making suggestions based on prognosis. In terms of prognosis, I was suggested to meet patients with very limited prognosis, one to three weeks; also, I was often referred patients who were considered 'difficult', rather than patients who would fulfil the criteria. Thus, I needed to change my recruitment approach.

Subsequent recruitment took place directly by me or patients themselves. Having been in the field for more than four months enabled me to have access to the ward's admission records and subsequently to patients' files as approval was already granted to access them by the ethics committees. I approached patients after their first day of admission over a routine thermometer round. In four cases, patients approached me requesting to take part in the study after discussions with other patients; two of them were not eligible, due to a better prognosis. It was very challenging to explain the reason for ineligibility as I had explained to those who had previously consented that I was interested in severe, long term illness (this is returned to in section 5.16 Ethical considerations).

I recruited a maximum of five patients at any one time in order to manage their follow-up and the load of participant observation. This decision was made after the first five participants were recruited when I realised that more participants at the same time would mean I would have to compromise the quality of observation and time spent with each of them. Thus, I recruited the final sample of 13 patients roughly in three slots, and conducted observations over a period of 25 months (Table 5-2). Ten patients were recruited from ward Mariza and four from ward Rallou. However, three of patients recruited from ward Mariza were admitted to ward Rallou during two of their admissions, so participant observation for these patients was conducted in both wards.

Table 5-2: Recruitment and follow-up over time

Patient	2005				2006												2007								
	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep
Ursula					x								x												
Kula													x												
Sila														x											
John																		x							
Con																									
Natasha																									
Fritos																									
Sotos																									
Giorgos																									
Pablo																									
Maria																									
Tamara																									
Mina																									
Observation of staff																									

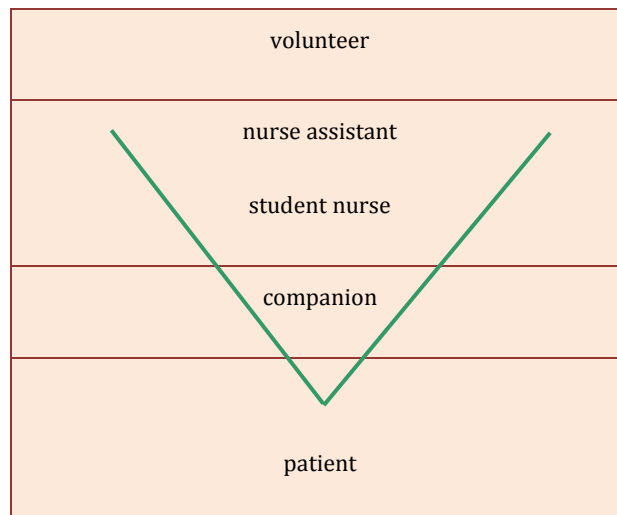
5.9 Role in the field

A key decision I had to make was in relation to the role I would adopt in the field. I had planned to take the role of a nurse assistant so that I would not have to take on any responsibilities for a patient's care, but rather be focussed on helping nurses with their work. A nurse assistant in Greece helps with making beds, washing patients, measuring temperature, and replenishing trolleys and cupboards in the nursing office. I would have preferred to be a volunteer, but this role does not exist in Greek hospitals and so is not familiar to nurses, doctors and patients. The role of assistant or volunteer had been adopted in a number of prior studies to good effect.

At the beginning of observation, the role of a nurse assistant was useful in order to follow the structure and work of the ward, but soon it proved to be quite confusing for both health professionals and patients. A nurse assistant is considered part of the team, and this meant I could not maintain flexibility in the degree of participation- observation. It also turned out to be problematic when I started interacting with patients. The nurse assistant had advanced duties within this setting, a role understood and accepted by patients. S/he could perform similar tasks to that of a staff nurse if this was necessary. That meant that, as a nurse assistant I should be able to perform IV and oral medication rounds, give information to patients about their treatment and help with blood tests. Even if, I did not wear the same uniform as a nurse assistant, patients identified me as a member of staff and requested my help with their care after only a week. This was stressful for me; I felt I was deceiving them, on the one hand, and on the other that I would fail them and lose my

research focus. After a discussion with the nurses, we decided that the role of a student nurse, in particular that of a postgraduate research student, would make things easier. This would differentiate me from being a member of staff and patients would be willing to trust me more than a student who had just entered nursing. At that point, this seemed important because I was told that patients were quite reluctant with student nurses because they felt as though they were being experimented on. Furthermore, many patients were familiar with questionnaires being administered by nurses doing their MSc course. Nonetheless, during participant observation with patients, I adopted the role of a companion to patients and families, and close relationships were developed (Figure 5-1).

Figure 5-1: Negotiated roles during participant observation



I carefully considered my appearance as this could influence people's perceptions of my role in the setting. I decided to wear a white robe which was quite different from the medical one and very different from a nursing uniform. In this way, I hoped I would mark myself out from being identified as a nurse and make clear that I had a specific role (Hammersley and Atkinson, 1995). On the other hand, I did not want to look out of place in a hospital environment where uniform is commonplace as this would probably obstruct merging into the world of the hospital and wards.

5.10 Negotiating identity - relationships

'A major problem was presenting the research in such way that permission would be given. As the Chief Constable considered certain topics too sensitive, we needed to be very careful in how we presented the research... Concerns about our motives were expressed... (Brewer, 2000, p583)

Almost immediately, I realised that negotiating access involved a process of presenting myself in the 'correct' way. Entrance could be denied if consciously or unconsciously I did not meet the cultural expectations of gatekeepers (Waddington, 1994). I understood that it was my responsibility to reinforce relationships with people whose natural environment it was. A willingness to learn people's ways helped in gaining trust. I tried to gain their trust on the basis of honesty, friendliness, openness and confidence building. Following the advice of previous researchers and a nurse who worked in this setting, I tried to be charming, confident but also modest; showing a willingness to learn and hear suggestions or comments; respecting their authority and requesting help and support. I was familiar with all these attitudes as they apply to clinical practice in most Greek hospitals and I had practiced them in the past in order to maintain satisfactory relationships with colleagues.

I realised I needed to maintain certain behaviour patterns with different groups of people in order to maintain smooth access and trust (Table 5-3). To be specific, management needed to be reassured that they would not get in trouble while the doctors needed me to confirm that their work load would not increase; on the other hand, nurses appreciated any helping hand. All health professionals worried about a judgemental attitude, something they had experienced in the past.

Table 5-3: Behaviour patterns adopted with different groups to facilitate relationships

Management and administration	<ul style="list-style-type: none"> -Being modest, let them feel they are helpful -Make them feel safe that they will not be faced with any responsibilities or adverse effects -Keeping a low profile
Doctors	<ul style="list-style-type: none"> -Being modest and scientific -Being unobtrusive -Using the less of their time
Nurses	<ul style="list-style-type: none"> -Being enthusiastic -Being helpful -Not being judgemental

The dual role of nurse and researcher brought challenges in relation to my identity in the field. Having been previously in a clinical post and now in the role of researcher in a clinical setting presented a challenge all of its own. Especially at the beginning, it was particularly tempting to convert from the role of the researcher to nurse. In fact, there were some incidences where I acted entirely as a nurse, when I responded to nurses' calls for help. Reflecting on my behaviour, I realised that I did not react as such driven by a sense of responsibility most of the time, but spontaneously due to prior clinical experience. I was aware that if trusting relationships were not built up, I could miss valuable information (Ingleton, 1997). However, my nursing background proved to be a useful tool to elicit information and to reinforce reciprocity with the nurses.

Other identities I held were of the girl coming from an island (very encouraging to nurses that had come to Athens from other places) and the role of daughter (an older nurse and mother were keen to help me as if I were her daughter). Tension was created within me when it was not clear to me which identities to withhold and which to preserve. Kirk and Miller (1986) discussed this situation as similar to identity crisis. However, with time, I realised that I could keep and utilise all those identities without necessarily raising conflict. I was a nurse, and I was a researcher. I could utilise my nursing role to help my researcher role. However, as a nurse I had developed a great deal of "taken for granted knowledge". Explanations and meanings might be influenced by perceptions I had

developed working as a nurse in the clinical field. That in turn, could influence my choices of what I observed or questioned when looking for meanings and justifications.

The changeability of roles and identities could bring with it an issue of the representation of my fieldwork. Reflexivity was, therefore, employed in order to diminish my personal bias. Post-modern ethnographers recognise that the observer's view is a view, and a view is sometimes better than no view (Brewer, 2000). Acknowledging that I could not avoid my personal representations, I tried to record them. A continuous, reflective diary was kept, and my own perceptions, assumptions, decisions and reflections were recorded in this way (Davies, 1999) (see more in section 5.17 Rigour).

5.11 Brief resume of data collection methods

The study employed a qualitative approach using an ethnographic methodological framework. Participant observation, formal and informal interviews and documents, such as patients' medical records and ward communication notes were also considered as means of data collection. These methods have been employed in ethnographic studies in palliative care in order to gain a broader perspective of a phenomenon, achieve a holistic view and enhance credibility of the findings (Armstrong-Coster, 2004, Lawton, 2000, Hockey, 1990). In brief, data collection consisted of:

i) Participant observation

Participant observation was conducted over a period of 25 months. This involved observing patients each time they entered an institutional health care setting. It also involved being present in some patients' homes. Families and health professionals involved in patients' care were also observed.

ii) Interviews

Interviews were conducted during the course of study with patients, family members and health professionals. A combination of informal and formal interviews was used. Informal interviews were used to clarify the context during participant observation but also to explore issues at the point they were raised by patients and families over time. Informal and formal interviews were recorded, and written notes were also used to document the nature of brief, informal interviews. Interviews were semi-structured based on themes emerging from participant observation and used with the aim of exploring participants' perceptions, feelings, thoughts and decisions.

iii) Documents

Medical records of patients were examined as a source of information on patients' experiences and perceptions of their illness and care from the perspective of health professionals. The use of these records aimed also to give an objective account of symptoms and explanations for certain behaviours.

5.12 Participant observation

Research observation involves the systematic selection, observation, and recording of behaviours, events and settings relevant to a problem under study. It is a method of collecting descriptive data of human behaviours or the characteristics of individuals, events, environments, or objects. (Polit and Beck, 2004)

Fieldwork for this study consisted of 480 hours of participant observation of healthcare professionals, during the first two introductory months of the study, 200 hours of participant observation during the main phase of data collection and 989 hours of participant observation with patients (details of each patient in Appendix 3).

As the aims of this study were to explore the care of dying patients and understand their experience of their dying trajectories, I had to follow participants until their death and accompany them through their journey. This meant I needed to follow patients to their encounters with every health care setting they were cared for in, throughout their last months of life. Therefore, participant observation took place mainly in two medical wards (which have been named Ward Mariza and Ward Rallou) and a day care clinic of an oncology hospital (main features described in Table 5-4). Additional data were also collected in the admissions office, the canteen and front yard of the hospital, the emergency room of two general hospitals, the cardiac clinic of another general hospital, a microbiology lab, the corridors outside of radiotherapy and X-Ray units of the hospital, patients' homes and two private health centres (see more in Chapter 5:Setting).

Table 5-4: Descriptors of setting for observation

An oncology hospital in Athens		
Ward Mariza	Ward Rallou	Day care clinic
<ul style="list-style-type: none"> • 33 beds • More and younger nurses • Younger patients mostly, having chemotherapy • Better facilities 	<ul style="list-style-type: none"> • 21 beds • Less and older nurses • Older patients, at end stage • Poorer facilities 	<ul style="list-style-type: none"> • 12 beds • 12 chairs

Participant observation was employed in this study to understand the complex phenomenon of patients' care (Table 5-5). It was used to explore the route patients and their families follow within the Greek health care setting in order to receive care needed. It was also very useful to record behaviours, actions and interaction among health professionals, patients and families and understand their dynamics. Moreover, it offered the opportunity to trace the everyday life of these patients and holistically understand their experience of care and illness. Additionally, observation of settings and circumstances in which behaviour were seen, were recorded in order to identify meanings and relationships to the social, economic and political context of the culture (Robertson and Boyle, 1984).

Table 5-5: Aspects of observation

Places	How it feels in the room, descriptions of the places and how the setting may influence what takes place.
Actors	What happens to people, how they behave, how they interpret it, what are the possible motivations.
Activities	Such as what takes place, how things are managed and what behaviours dominate.



5.12.1 Degree of participation

I wanted a role that would enable me to be close enough to participants so that they could share with me their views and thoughts freely but at the same time I wanted to be distant enough in order to be able to observe. During the first phase, I tried various degrees of participation. When I first entered the ward, I was a complete observer as I was trying to make sense of what was happening. After the first week, I adopted the role more of a participant. I needed to fit in with the nursing team and develop an understanding of their environment and work. I wanted them to feel comfortable with me. I acknowledged that trusting relationships and a non-judgemental attitude on my part were essential in order to gain an understanding of the participants' world (Wolcott, 1995). Moreover, establishing rapport between the observer and subjects could decrease the observer's effect (Brewer, 2000). I spent two weeks shadowing nurses, and then assisting them in order to gain a nurse perspective on how care was organised and delivered. When I felt comfortable with the ward environment and developed an understanding of how and where to stand, but also had started developing trusting relationships with nurses, I felt more confident to begin to adopt the role of participant observer. Going repeatedly back to my aims and objectives helped me in focusing my thinking.

I realised that participation and observation were not necessarily starkly opposed, but have a reciprocal relationship. Moore and Savage (2002) suggest that participation can bring about change in the researcher leading to new observation while this new observation in turn changes how s/he participates. As Polit and Beck support (2004), most

of the fieldwork lay between the two extremes and shifted over time in emphasis between observation and participation. In this study, I adopted more of the observer role when I was establishing myself in a new field and, therefore, sought to capture the macro level, the broader picture of the setting; or when I was interested in pure facts, such as how many people had walked in the clinic, or how much time nurses spent next to the patients. On the other hand, I chose to focus more on participation when I needed to maintain reciprocity with participants, or when I wished to explore feelings and understand perceptions and decision-making (Table 5-6).

Table 5-6: Adjusting types of participant observation according to fieldwork needs

Observation 	 Participation
<ul style="list-style-type: none"> ● When establishing myself in a new field 	<ul style="list-style-type: none"> ● When trying to maintain reciprocity
<ul style="list-style-type: none"> ● When seeking of capturing the macro level/ the broader picture 	<ul style="list-style-type: none"> ● When looking at the micro level/ a very focused picture
<ul style="list-style-type: none"> ● When interested in pure facts 	<ul style="list-style-type: none"> ● When interested in understanding feelings, perceptions, decisions

Wolcott (Wolcott, 1995, Wolcott, 1999) suggested three different types of participation: from active to privileged and limited participation. The active observer is the one of having a job within the setting of study; the privileged observer is known and trusted and is given easy access to information while the limited observer has no role other than that of a researcher observing and asking questions. I mostly developed the role of observer as a participant, as I marginally participated (did not become a member of staff of the health care setting). After the first month, I was mostly becoming a privileged observer as trusting relationships had been developed and thus participants shared thoughts,

information and feelings. However, when I adopted the role of companion or on occasion replaced the family carer for some hours, I turned to an active observer.

5.12.2 Development of observation over time

I started my observation in September 2005, and it lasted until September 2007. During the first two weeks, I spent time with nurses in their office and the place where they prepared for their rounds and other interventions. As I was not yet familiar with the environment or the delivered care, I felt it would not be fruitful to observe interactions with patients. Thus, I first tried to familiarise myself with the physical setting and the structure of nursing work. I also used that time to get to know nurses and for them to know me in order to gain their trust. My first recordings were about what was going on in general and how I felt about the place. The first two weeks were a time to understand the physical construction of the place, orientate myself, and learn who was who.

After the first couple of weeks, I felt I could then move closer to patients' rooms and observe nursing practice and interactions. I was more familiar with the patients cared for on the ward as I had followed handovers closely. Yet, I did not feel ready to move to recruitment; I wanted to give more time to nurses as they had started sharing with me their experiences and problems. Thus, the first two months I interrelated mostly with nurses. The nurses who were interacting more with patients invited me to shadow them. Two nurses in particular encouraged me to follow them and were keen to explain what they did and why. Every time we approached a patient, the nurse would explain that I was a researcher who follows nurses at work and asked their consent in order for me to observe. No patient objected to my presence, and many patients had already known about me as they had asked the nurses if I was a new member of the team. After some time, health care assistants suggested I could help with some of their work, something which would enable me to come closer to patients' rooms and interactions with patients. Besides, I had offered to help with general matters, such as filling up their trolleys or taking paperwork around.

After the first month in the field, I followed one patient as a pilot case. The patient had approached me by herself and offered to become part of the study. Nurses encouraged this communication, with one more argument; the patient had no family and thus they thought it would be beneficial for her to have someone to talk to.

During the first weeks, I experimented with time and length of participant observation. I was at the ward for three to four hours per day, four days a week. I expanded observation sessions over the nursing rota so that I would observe nursing work during all shifts; three shifts per day. This proved quite helpful in building up strong relationships as nurses appreciated the fact that I was making such an effort to understand their world. Moreover, during afternoon shifts the workload was less and thus we had more time for discuss. Also, over the afternoon and night shifts, I got the chance to become acquainted with the doctors on call.

I did not record my field notes in front of the people during the first period of data collection. I used the excuse to go to the toilet or the canteen for coffee. When I helped with the paperwork, I managed to write down a few jottings which I completed after the end of the observation session. When I was comfortable with my presence in the ward, but also with participant observation, I experimented more with the length of observation and the frequency of visits. Eventually, I decided to opt for three days a week of observation and thus, I developed a pace with which I could cope in terms of thinking, reading and reflecting.

When I moved on with patient recruitment, I organised fieldwork around them primarily. The pilot case helped me to become familiar with differences with regards to relationship growth and observation. I knew I needed to develop a relationship which would allow me to follow patients over time while reducing the possibility of their withdrawal. The second and third patients were recruited during the same week. I quickly realised that if I wanted to keep communication, I had to gain the support of the family. They took me aside to ask

me about the research and argued that they were there to protect their relatives from potential harm or useless exposure to things. Giving them the opportunity to express their views, values and feelings helped with gaining their trust. This experience made me aware of the role of the family as a gatekeeper.

My role and time spent observing next to patients developed gradually over time. It shifted from researcher, to health assistant, to that of a trusted companion; in this latter role I often shared intimate thoughts and feelings and followed the journey until death. I was involved with patients every time they came in contact with the hospital. At the beginning, nurses would inform me about their re-admission if I was not there, but later on, patients or their families called me to let me know. This was extremely helpful in situations where there had been an emergency. I visited patients every day during their admission to hospital and sometimes, twice a day (over morning and afternoon shifts). In between admissions, I had phone calls and occasionally a visit to their home.

I followed patients until their death, being a witness of their death in most cases and going to their funerals as the aims of the study were to understand patients' dying journey and explore their care and experience throughout. I also visited families a few weeks after the funeral. The time I spent with individual patients until their death varied from three weeks to six months (Table 5-7). Participant observation varied from some hours per day during early stages of enrolment and intensified nearer the end. As close relationships were developed over time, both families and patients wanted me next to them; they wanted me to become a witness of their story with the aim of helping other people in the future. Also, some patients expressed that if I wanted to understand their journey, I would need to remain close while things got tough for them.

Table 5-7: Length of data collection with individual patients

<i>n</i> patients	Duration of data collection
3	3 weeks-1 month
6	1-3 months
4	3-6 months

During the 25 months of participant observation, I tried to keep my aims and objectives in mind whilst in the field. I kept writing questions in my notebook after an observation session and before embarking on the next one, so that my observations would be informed, rather than going native in the field. Questions at the beginning were broader, and as fieldwork evolved, they became more specific while being revised in relation to data collected so far. Such questions were ‘what is important for this patient and his-her family, what does everyday life consist of for the patient, what is the care provided at this time point, what are health care professionals’ perceptions in relation to patients needs now’? When other aspects were revealed and connections started appearing, I explored questions such as ‘what am I learning about the participant now? What is the same, what is different? How and why did it change? Who is making the decisions of care, place of care and place of death and why? How does this influence patient’ experience and the journey itself? These are some of the questions raised when in the field and continued throughout subsequent formal analysis.

5.12.3 Field notes

In keeping with best practice, field notes were developed over the period of the study, reflecting the time spent with patients, families and health professionals for 25 months.

The field notes I kept were both descriptive and reflective. Following Atkinson’s distinction (1992), I tried to include in my descriptive field notes both *inscriptions* and *transcriptions*. Inscriptions incorporated the written accounts that represented events, activities, scenes, objects, people, and settings in some portion of the social world of the

wards while transcriptions consisted of the representations of some social actors' own words, i.e. patients', family members', nurses', doctors and other health professionals' words. Nevertheless, I considered reflective field notes equally essential in order to assure the rigour of the study (see more in section 5.17 Rigour). I recorded reflections about the strategies and methods used in the observation- *methodological notes*; I also documented my own thoughts about how to make sense of what was going on in an effort to attach meaning to observation and also serve as a starting point for analysis- *theoretical notes*. Finally, I kept reflective notes about my own feelings while being in the field- *personal notes* in a reflective diary (Polit and Beck, 2004). Field experiences gave rise to personal emotions and challenged assumptions. Since the pilot phase, it became clear to me that reflecting on my feelings was a useful tool to determine whether feelings were influencing what was being observed or what was being done in the participant role. Often, my recorded emotions mirrored those that occurred in the setting.. Moreover, reflexive diary helped me to identify biases or prejudices, as well as changing attitudes towards people and events. Personal notes also included ethical dilemmas and conflicts within my roles.

Since the success of participant observation relies substantially on the quality of field notes (Strauss and Corbin, 1990), I followed some rules when writing them. Field notes were written as soon as possible after the observation session. Thus, memory bias, either as forgotten details or effect of subsequently events, could be reduced (Polit and Beck, 2004). Additionally, jotted notes were kept during the observation in a little note book I always carried in my pocket. "Jottings translate to be-remembered observations into writing as quickly rendered scribbles about actions and dialogue" (Emerson et al., 2001, p356). Participants' verbatim was indicated by quotations in order to keep a certain level of accuracy (Brewer, 2000). Finally, a system for recoding and managing the substantial amount of field notes was developed. Each entry had the date and time of the observation session and a title or some key words that triggered my memory.

5.13 Interviews

I interviewed all patients, the key health professionals involved in their care, as well as families at several time-points over the 22 months of fieldwork. In this way, an effort was made to secure multiple perspectives of all those closely involved in a patient's care.

Given that ethnography is an inductive research approach, I avoided a-priori standardisation of technique and assumptions of data and concepts (Brewer, 2000). I remained open to adapting the methods of collecting data to situations as they unfolded in the field, and create or add new procedures of data collection (Soenen, 2002, LeCompte and Goetz J, 2001).

5.13.1 Structure of interviews

Interviews conducted during the course of study ranged from structured (formal) to semi-structured and unstructured (informal). The different types of interviews were chosen depending on the participants' condition; the interview purpose and the needs revealed during specific situations. They aimed to capture and explore participants' feelings, perceptions, thoughts and decision-making aimed to over time (Heyl, 2001). They were used as a means of exploring the meanings participants placed on events and their worlds; they also helped with discovering some of the cultural meanings participants had learned and acted on.

The unstructured discussions had the form of conversations and aimed to encourage participants to disclose aspects of their experience which were important to them; also information in relation to care and illness which they found relevant to them, rather than being guided by the researcher's perceptions (Polit and Beck, 2004). The purpose of the study was neither to reveal individual secrets nor to be critical of particular health care services or individual providers. It was rather to describe, at a given point in time, the experiences of thirteen patients and their families.

Semi- structured interviews were carried out when I needed to cover specific topics, or clarify specific issues and meanings that have occurred from previous interviews and the fieldwork observations. Participant observation helped to plan the interviews; themes emerging from participant observation formed the basis of semi structured interviews so that thoughts, understandings could be clarified and thought through at a deeper level (Brewer, 2000). Initially a topic guide was prepared with a list of questions or areas that needed to be covered and probes designed in order to elicit more detailed information, but at the same time allow the interviewees to provide as many details, illustrations or explanations as they wished (Brewer 2002). However, over the period of data collection, many more questions were raised, and as perceptions and feelings shifted over time, new questions were formed (see Appendix 4 for interview topic guides).

However, most encounters with patients took place in the hospital setting, something that made me realise that there was a strong possibility of a perceived asymmetry of knowledge and/or status. Participants' empowerment was vital to minimise the power effect of the interviewer (Mischler, 1986). Following levels of empowerment offered by Mischler (1986) and Heyl (2001), I gradually moved from the role of a '*the informant/reporter relationship*', to the '*research collaborators relationship*'. At the beginning of my relationship with participants, I adopted the role of the reporter with the aim to report on participants' understandings. At those times, I conducted informal interviews. I encouraged participants to 'name' the world in their own terms rather than reacting to terminology or categories I possibly introduced. Often I reminded them that they were the experts, and I was there to listen and learn; to understand and record their views, thoughts and experiences.

Nevertheless, over the course of data collection, I realised that participants influenced the content and order of the questions and topics covered. The participants participated in interpreting and re- interpreting questions and responses, clarifying what their responses meant, and even re-framing the research question. Such a perception was assisted by me

presenting my visit with the form of everyday conversation rather than interview. At those times, we had more of informal discussions rather than interviews. Thereby, my role evolved from the one of the researcher to a companion.

5.13.2 Formal interviews

Formal interviews consist of 12 interviews with patients; five interviews with two medical consultants; two with SHOs; two with the psychiatrist of the hospital; and two with the head of the social services of the hospital; and one with the sister of the day care clinic.

Formal interviews were carried out with senior doctors who expressed worries over the time commitment that frequent informal discussions might entail. They preferred a more structured process. All formal interviews took place either in doctors' offices, the nursing offices, the social worker's office and the ward's storage room for the health professionals. The length of formal interviews varied from fifty minutes to ninety minutes.

I also wanted to interview formally patients, when there would be many questions to be addressed, and at the near their recruitment point. Thus, I would have a base to compare to in future interviews, but also I could gain a general picture of them, and perhaps information on the period before recruitment. I conducted four formal interviews with patients. One interview was not completed as the patient felt she did not want to continue with it. She expressed feelings of stress but also tiredness and requested to return to her bed. Reflecting on that incident, I decided not to continue with formal interviewing patients. First it was extremely difficult to secure a private space for patients, and in that case, they needed to be away from their bed for a while. Also, formal interviews could not reflect the momentum of a situation as they could not be arranged simultaneously and thus they were out of context, something that informal ones could provide effectively. For these reasons, I mainly followed patients with informal interviews and discussions. It was also the patients themselves who encouraged informal interviews (see following section).

5.13.3 Informal interviews and group discussions

Informal interviews were used with junior doctors, nurses, patients and family members and were audio recorded. The informal interviews intended to facilitate the establishment of trusting relationships with participants and to allow a genuine exchange of views (Brewer 2000). Also, they facilitated explanations at nearly the time at which issues were raised. Additionally they allowed me to remain unobtrusive as they did not demand much of health professionals' time. However, I could only employ them when health professionals were already familiar with audio-recording and felt quite comfortable with the recorder being switched on for just for five minutes. The informal interviews took place in the nursing offices for nurses and doctors.

Informal interviews were also employed for patients. They were particularly useful when patients were too tired to focus for more than half an hour. Moreover, informal interviews proved to be highly effective to clarify the context during participant observation, or to explore themes that emerged during preliminary data analysis. Also, it provided me with the flexibility to explore issues pertinent to patients and their families at the specific point, but also explore meanings, feelings, perceptions on their own pace and system of priorities. They were also particularly helpful in clarifying or covering topics which had emerged from previous interviews and/or the observational data.

Informal interviews took place either with patients and families separately or together, depending on their wishes. I also made sure that I visited patients when they were alone, in order to secure their true thoughts. In fact, there were situations where patients had altered their responses in front of families, either to protect them (death and dying issues) or when they referred to sensitive personal data. When relationships were established, it was the patients who often indicated a time I could come back and speak to them alone. I recorded similar behaviours from the families.

Informal interviews took place in patients' rooms, or while waiting for a test in an outpatient setting, the corridors and occasionally at patients' homes. I interviewed family members either in the ward or kitchen; the front yard or a quiet spot of a corridor, especially when I wished to talk to them separately from patients. The length of informal interviews- depended on the purpose- varied from five minutes two 75 min.

A respectable part of the interview data consisted of free discussions. It comprised of more than fifty discussions with patients at different time points of their journey. These discussions lasted from ten to ninety minutes. Most of them happened spontaneously while shadowing nurses, or while observing patients and families. Quite often, such discussions took place every time I entered the field, and participants wanted to inform me about incidents happened in my absence.

In terms of free discussions with patients, it was they who came up with this idea. I did not aim to audio record those discussions, rather than include them in my field notes over participant observation. Once, a patient said he would like to discuss something and that I could record it as it could be useful to me. I realised that such discussions could be immensely fruitful in terms of letting patients introducing their own thoughts, feelings, themes, rather than me imposing my own concerns, or questions and priorities. From that moment, I applied this technique with all patients and families. They reported that those informal discussions were very interesting or even enjoyable for them as they felt they had a more active role, but also they felt more accompanied in their journey rather than being researched.

Several group discussions between nurses and between two or more doctors were also facilitated. I decided to follow such group discussions after an incident I had with one of the patients. It was after midnight while waiting for a patient to die. At one point, when in the nursing office, I started asking a nurse about her perceptions on the dying patients' last moments and her feelings around such times. The rest of nurses and the doctor on call,

who came in the office, found such a discussion extremely interesting and offered to participate. They were quite happy with my recording it as felt relaxed in the presence of colleagues. This discussion provided exceptionally rich information in relation to health professionals' attitude about death and dying, their unease around such moments, and their perceptions of their role in patients' dying moments. During that discussion, health professionals reflected on their practices and suggested future solutions. That incident encouraged me to use this technique several more times with nurses. Those group discussions took place during handovers while I offered juices and snacks.

5.13.4 Audio recording

I recorded both formal and informal interviews as well as group discussions that took place with patients, families, nurses and occasionally with doctors. Audio recordings consisted of 45 hours of audio files with health professionals and 131 hours with patients and their families. Additionally, conversations and interactions between patients, health professionals and family members were recorded during the time of participant observation. Overall, conversations with participants were audio-recorded in medical offices, nursing offices, patients' rooms, or while waiting for a test in an outpatient setting or at patients' homes.

I followed different practises within taping with the three groups of participants- doctors, nurses and patients/ families. Health professionals were not used to be interviewed and they found it very uncomfortable. Thus, we started with informal interviews or group discussions. Later, I focused on taping those discussions while starting interviewing some nurses. Patients and families were not comfortable at the beginning either, but after some time, they invited me to record all conversations. Both doctors and nurses were more comfortable with group taping in informal discussions initially. Nurses had not the experience of being recorded before, and thus they found tape recording stressful. Playing with the recorder relaxed them; I first recorded them joking and singing and when they felt familiar with the presence of the recorder, we recorded 'neutral activities' such as

handovers. The next step was to record group discussions and when fully trusted I was suggested to interview them privately. Consultant doctors agreed easily to give a formal interview to express their beliefs and values of their clinics. Nevertheless, they were not happy to be interviewed repeatedly due to time constraints. Senior house officers found easier with group interviewing after a few months of my presence. When I mentioned plans to leave the field, they invited me to interview them. They explained that they felt there was always time for later on. They agreed with tape recording when I offered them control of the digital recorder and promised a digital copy of their interview. As with patients and families, I started with informal discussions over the first days. After the first days of accommodating of each other, I started keeping notes of our discussions. When the patients seemed comfortable with keeping notes, I requested to tape. Finally, I was invited to tape discussions. I followed the same pattern with families. Most of the recordings with patients were informal discussions as they often stated they were quite tired; hence we chose to tape our discussions wherever they felt comfortable to lie or sit.

I personally transcribed most of the interview data and translated several of them in order to receive guidance and help by my supervisors. Interviews were filed under the name of each participant, with the date and time and audio number of each recording. A title was given to each recording so that I could trace relevant data during the analysis process. All names were changed in order to secure anonymity (see also ethical considerations).

5.14 Documents

Medical and nursing records such as patients' charts, physicians' and nurses' orders, care plan statements, shift reports, as well as health care and hospital policies, were also considered. I consulted medical records of patients when trying to identify potential participants but also when looking for similarities and differences in patients' experiences and perceptions of their illness and care with those of health professionals. The medical records and nursing notes were useful as they gave an account of both symptoms and illness and also explanations for certain behaviours, through the eyes of health

professionals. However, as Polit and Beck (2004) advice, I did not use those records as solid evidence as there is always a possibility of bias within these records. The records kept were not necessarily representative as they were often incomplete and thus might have introduced systematic bias (Polit and Beck, 2004). Nevertheless, they were informative in relation to the route of care for patients, such as the number of visits to each health care setting, the number of settings and the type of health professionals involved, waiting times to appointments and days spent in the hospital. Also, they gave me an indication of the health professionals' perception of what was pertinent to report, of what their role consisted of in relation to patient's care and of their understanding of patients' symptoms, such as pain. They provoked fruitful discussions with health professionals with regards to their own beliefs and views concerning the needs and care of patients.

5.15 Data analysis

Robertson and Boyle (1984) suggest that the primary goal of ethnography is attaining rich data leading to an in-depth descriptive analysis of cultural phenomena. The ethnographer should continually strive to cover the full range of the phenomena under study so that the resulting interpretation will lead to a meaningful, in-depth understanding of the culture. Gubrium and Holstein (2003) take this a bit further, arguing that the analysis is more than a matter of classifying, categorising, or coding data. Instead, the analysis should be essentially about the representation and reconstruction of the social phenomena. Consequently, ethnographers should not report only what they find but create accounts and reconstruct versions of the social world they observe and interact with.

A preliminary data analysis was carried out concurrently with data collection as I tried to make sense of the everyday reality of care and experience of the participants. Moreover, preliminary data analysis was necessary in order to inform the interviews and guide the ongoing observation (Brewer, 2000, Holloway and Wheeler, 1996). The preliminary

analysis started during participant observation (Hammersley and Atkinson, 1995). Analytic memos were written each time field notes were recorded and led to the first ideas for analysis. Through the analytic memos, I started to identify themes, which were based, on phrases or words participants had used while giving meanings to their actions and interactions.

After the 22 months of data collection, I analysed the data using thematic analysis. Although content analysis can be a valid method to use, it carries the risk of remaining at a relatively superficial level and drawing more attention to the frequency with which certain aspects of a phenomenon occur, rather than supporting the understanding of the phenomenon as a whole. On the other hand, thematic analysis is a more exploratory, rich and insightful method of qualitative analysis; it was chosen because it allowed for recognition of themes and common elements in textual data. It can also provide meaningful and organisational structure (Flick, 2009).

I analysed both interview transcriptions and field notes line-by-line. Field notes helped with contextualising the interview data, by bringing in information about events, places and actors. It also helped with verifying or contradicting interview data. Observational data offered the opportunity to develop guides and questions for succeeding interviews, and also provided a base for making connections between different actors and themes. I looked at each participant's data separately, and then across participants. I grouped participants into four different groups - patients, families, nurses, and doctors - so I could compare and contrast themes across groups, with a view to understand and make apparent the multi vocality of reality as it was constructed over time.

I followed the thematic analysis process as proposed by Attride-Stirling (2001). The process consisted of three broad stages a) breakdown of the text or reduction of text, b) the exploration of the text and c) the reconstruction-integration of exploration. Detailed steps are described below.

Familiarise with the data: First, I familiarised myself with the data. This took place over several weeks. I read and re-read the transcripts and field notes while making additional reflective comments on the nature and content of the data. I used the margins to note anything compelling or significant so that broader meanings would be generated.

Develop the coding index: After being familiar with the data, I looked for words, phrases, ideas or examples which could identify potential themes (i.e. keys that capture the essence of the text). In this way, a coding index was developed. As the process evolved, new categories arose which challenge existing themes or added more. At initial stages of this process, new categories were identified, and the coding index was constantly modified.

Manage the data using a qualitative data software package: Managing the load of data proved to be challenging. To support this process, I used NVivo (version 8). I imported the data and codes, and used both paper and the NVivo electronic files for analysing the data into themes.

Abstract themes: Once the codes were imported into NVivo, I abstracted themes from the coded text segments. I also extracted the data into different Word folders under the heading of one theme. In this way, I could reframe the reading of the text, which enabled me to identify underlying patterns and structures. Some themes had a more coherent description; others remained a one word note. The themes were expanded or contrasted and changed whilst analysing more data. Over time, more examples were added which either enriched the theme, or changed it.

Refine themes: The data attached to the initial themes were reviewed separately in detail. The content of each extract was considered by going back to the initial field note or interview. Themes were refined as to be specific enough to be discrete, but also broad enough to encapsulate a set of codes contained in numerous text segments. Within this process, themes changed or collapsed into another theme, or sub-divided further. A list of

themes and their sub-themes emerged. Some of the sub-themes could be shared by more than one theme, which might indicate possible relations between the themes.

Create thematic networks: After developing and refining the themes, I grouped them together under broader categories (organising themes), and clustered subsequently into broader domains (global themes) using the technique of thematic network. This grouping of themes was done on the basis of content. The five global themes referred to the study objectives: experience of care, experience of illness, illness trajectory, care provision and everyday life. This helped to summarise particular themes in order to create larger, unifying themes and condense the concepts and ideas mentioned at a lower level (Attride-Stirling, 2001). I used the same process of developing and refining themes to verify and refine the thematic networks.

Explore thematic networks: After thematic networks were developed, I added to them the original text segments to ground the findings in the data and describe them further. This enabled my supervisors to review the analysis process. I went back to the original text reading it through the thematic networks and explored underlying patterns which begun to emerge. I looked for associations and patterns in the data to provide explanations. In this way, I aimed to bring close together the data and the interpretations made.

5.16 Ethical considerations

5.16.1 Ethics committees

Ethical approvals were gained from the King's College London Research Ethics Committee (ref no. 04/05-122, application and approval letter in Appendix 5) and subsequently the hospital Scientific Committee. The latter approved the study in December 2005 (ref no. 14387/ φ. 416/9-11-2005; application and approval letter in Appendix 2). The procedures of applying to the Greek Scientific Committee are presented in Appendix 6.

5.16.2 Informed consent

According to ethics committees, participants should receive an information sheet before they decide to get involved in the study and their consent should be obtained written before they decide to take part. Information sheets were prepared separately for health professionals and patients and families. Both consent forms and information sheets were translated into Greek.

All parties received information which specified the aims and details of the study (Appendix 7). Patients and families received the same information sheet as it was not possible to separate them in the Greek context. Otherwise, access and trust of participants could be jeopardised. Moreover, as I anticipated and later confirmed, in Greece patients did not always acknowledge their diagnosis and prognosis; thus, the information sheet did not include the words 'cancer' or 'terminal illness', but instead use the term 'serious illness with possible chronic effects'. Nonetheless, all patients with the exception of two were aware of their diagnosis, and as the disease progressed, they discussed with me issues about death and dying even though they did not admit to their families.

Health professionals were pleased with the information sheets and all nurses - with the exception of three in the ward Mariza - signed the consent forms. Both nurses and doctors felt they did not have to sign any forms in an expression of good will and trust. After I insisted that I would need this evidence for the British university, they signed the forms.

However, patients and families felt uncomfortable with information sheets and consent forms. They preferred discussions about the study rather than information sheets. They found them impersonal and distant. Consent forms at the beginning of the study were perceived as requesting them to take the responsibility of the possible adverse effects of the study rather than as a means of their protection. They felt it was something similar with when they had to consent for interventions.

For these reasons, I chose to explain the study in detail during face to face discussions. After they had confirmed they would like to take part, I gave them the information sheets and consent forms. I was told that signing a form to protect themselves would be quite insulting for me as that could be interpreted as a lack of trust on my behalf. When I explained that I needed to follow this procedure for the ethics committees they agreed, so that could help me. Only three patients who were familiar with research (postgraduate student, professor, a degree in psychology) accepted the consent forms at the beginning.

Nevertheless, consent forms are not adequate to secure participant consent. As Raudonis supported (1992), a continuous process of consent needed to be followed, especially with vulnerable groups such as palliative care patients during a longitudinal study. Thus, consent was sought not only at the start of data collection, but it was reconfirmed on an ongoing basis with all participants during data collection (Wiseman, 2002, Raudonis, 1992). There were two occasions where participants refused to be recorded at a specific point. The first was a nurse during handover, where she reported sensitive information in relation to some of her colleagues over that shift. The second case was with one patient when he revealed intimate personal information.

5.16.3 Withdrawal

It was stressed to participants they could withdraw at any time and that any information about them would be withdrawn if they wished. There were no requests to withdraw information. Also, I considered withdrawing closer to patients' death out of respect to the privacy of the moment, but patients and families requested me to stay next to them until the end. Otherwise, it was perceived as abandoning them. Hence, I witnessed almost all deaths of participants.

5.16.4 Privacy

The participants' right to privacy must also be respected, which can be easily invaded once they have given consent. Punch (1994) clarified that the right to privacy refers to a

participant's choice of how much of themselves (including thoughts, emotions, attitudes, physical presence and personal facts) they are willing to share with others. All these were explained and repeated often to participants while reaffirming consent. It was made clear to participants that they had the right to ask me to leave at any point if they felt my presence was inappropriate, and that would neither insult me, nor would influence my attitude towards them. That was particularly relevant especially with those who I developed a close relationship and might feel they might insult me.

5.16.5 Beneficence/non-maleficence

Cassel (2001) addresses ethical dilemmas in terms of beneficence and non-maleficence. Patients were informed they would not benefit from this study, but findings would be used to develop recommendations on future care of this group. Five participants expressed that by participating in this study, they felt useful and gained interest by adopting a new role. They also said they felt respected, as the centre of this study was their experience, their views and feelings. Two patients felt that this was an achievement for them.

'I want you to write my story and put my name on; that would be the last accomplishment in life; helping for a better care' (Pavlos; quote in field notes; 20 days before death)

When considering harm, Murphy and Dingwall (2001) underlines that participants may experience stress and anxiety during data collection. Participants may feel embarrassed about opinions they hold or choices they make. In order to avoid such an event, I tried not judge their actions and thoughts and values. There were two incidences where the interviews became intense; the first occasion was when a patient described problems in the relationship with her husband and the second one were when the wife of a patient recalled traumatic experiences from her childhood. In both cases, debriefing session was offered, and in the second case, the participant was encouraged to take it further with a psychologist who had already followed her.

5.16.6 Confidentiality and anonymity

Participants' anonymity and confidentiality are two key issues and have been recognised as a particular issue within ethnography (Hammersley and Atkinson, 1995, Davies, 1999). Participants were assured that all information given would be kept confidential from the rest of participants, families and health providers or patients respectively. Also, I often reminded participants that if they had any request over some aspect or part of an interview to be kept confidential and not used as data, I would respect this.

To secure confidentiality, no names were indicated on the audio files but instead given pseudo names (ID codes). The names of participants with their given ID codes were kept separately in a locked cupboard. The data were kept in a closed locked drawer and on my computer secured with a password. Only my supervisors and I had access to the data. Finally, the audio files of interviews were destroyed after data analysis and field notes, and transcripts will be archived for seven years under the management of my supervisors.

Anonymity should be also secured when writing up an ethnography. Efforts were made so that settings, participants and specific services could not be identified by readers.

5.17 Rigour

5.17.1 Reflexivity

It is acknowledged within social research that researchers are part of the world they study (Creswell, 2003, Kennedy, 1999, Hammersley and Atkinson, 1995). Being part of the world they study, the researchers cannot separate themselves from it, nor eliminate their effects (Hammersley and Atkinson, 1983). Social construction and analytical realism have supported that knowledge is contextual (see more in sections 4.2 Theoretical framework and 4.3 Epistemological framework), thus a researcher's perspective must be specified as much as that of his/her subjects' so that 'validity as reflexive-accounting' will be ensured. Reflexivity, therefore, has been introduced to answer debates concerning the

representation and authority of the ethnographic text and ensure rigour (Altheide and Johnson, 1998, Hammersley and Atkinson, 1983).

As Brewer encourages (Brewer, 2000), I have tried to be reflexive to my own account of the research process, the data collected, and the way I have written it up, because reflexivity shows the partial nature of my representation of reality and the multiplicity of competing versions of reality. Thus, reflexivity was implemented as a way of improving legitimacy of the data (Denzin, 1998). Reflexivity in both data collection and analysis may provide evidence of rigour (Pellatt, 2003).

Polit & Beck (2004) distinguishes reflexivity into two principal categories: *descriptive* and *analytical*. Descriptive reflexivity involves description of the social location of the research, the preconceptions of the researcher, power relations in the field and the nature of interaction between the researcher and participants. Analytical reflexivity requires a form of intellectual autobiography in which the researcher should explicate the processes by which understanding and interpretation was reached and how any changed understanding from prior preconceptions came about (Karp and Kendall, 2001).

I sought to be reflexive in both descriptive and analytical senses. Following Altheide and Johnson (1998) I kept a reflective diary in which I reflected on issues such as:

- the wider relevance of the health care system to settings and the topic of the research, the representativeness of the settings the patients were submitted and their function as particular cases with a broader bearing;
- the length of fieldwork, the special access negotiated, the extent of trust and rapport developed with the participants, my background and experience in the settings and topic and my experiences during all stages of the research;
- the data: problems occurring during all stages of the research, identify the categorisation system used to interpret the data, providing sufficient data extracts

in text to allow readers make their own evaluations, discussing power relations between participants and me and how that may affect the data;

- the capacity/identity with which I was present and the place I occupied in these events
- My feelings, impressions and understandings.

Reflexivity proved to be a way of learning myself. Unease or unexpected emotions occasionally occurred which I had not faced before. Keeping a reflexive diary separate from the reflexive notes was sometimes easier as I did not have to separate the descriptive parts and I could narrate combining the events and my feelings, actions, etc. I also realised that finding the right pace means finding also the pace at which you feel comfortable with dealing with critical reflection. I came to realise that participant observation is conscious work requiring the observer to understand the process of transformation which s/he undergoes by being present in the field. I discovered that by being reflexive and reviewing my field notes and diary, I could ask questions of the data, understand and audit the process of research and trace the transformation of myself through my decision-making. That proved very helpful to the process of analysis.

5.17.2 Piloting

The pilot period of observation enhanced rigour. A number of ethnographers have advocated a period of pilot work to work out the practicalities of participant observation, such as where to stand, how long to observe who and what to observe (Kelly, 2002, Wiseman, 2002, Lawton, 2000). The pilot period clarified issues such the appropriateness of the role I wanted to adopt in participant observation. Furthermore, it verified the suitability of the information sheets and consents forms for Greek patients and families. The pilot case helped me to understand the balance between boundaries and reciprocity in the researcher- patient relationship. Furthermore, it gave me the opportunity to practice on revising and adapting the interview and observation guides.

5.17.3 Maintaining pace

As the researcher, I was the means of data collection and issues such as gaining trust, keeping pace with data collection and emotional involvement were influential to the quality and validity of data (Tobin and Begley, 2004). Moreover, collecting high quality data required intense concentration and energy. The process of collecting data was emotionally straining at times, particularly when sensitive issues were explored and near the end of life of patients. Therefore, a pace that minimised the emotional impact on me personally was maintained.

5.17.4 Communication-observation skills

Bowling (2004) emphasizes that researchers should receive training in communication skills before interviewing and in recording observational data for purposes of assuring validity. I had attended a course of communication skills in research. Also, supervision over the first set of transcribed interviews helped me improve my skills. In terms of observation, I recorded observations parallel with one of my supervisors when she was in fieldwork. That helped me practice how to organise an observation session. Comparison of both recordings helped me realise potential biases I might introduce.

5.18 Authenticity of the study

As postmodern researchers have illustrated, qualitative research should encourage readers themselves to judge whether they consider findings to be authentic, believable, or indeed possible. In helping to judging the authenticity of this study, the following points have been incorporated into the thesis:

- My own background and motivation for the study have been made clear;
- The process of enquiry, including methodological choices discussed;
- Reflexivity was employed to record my decision-making, feelings and thoughts during the course of the study;

-
- Analytical processes have been detailed;
 - Common experiences have been highlighted and contrasted with those which deviated from individual cases ;
 - The context of the study has been explained;
 - The findings have included sufficient quotes so that readers may judge for themselves for the interpretations made;
 - The limitations of the study are acknowledged when conclusions are drawn.

This study intended to explore the dying processes of patients with advanced cancer in a Greek oncology hospital, explore the care they received and understand their experience of care and illness, as well as their impact on their everyday life. It is only possible to represent the world as I observed and experienced it (Rudge, 1996). This ethnography is my reality as it represented myself and my analysis which remains grounded in the data. Undoubtedly, others might have chosen to address the topic differently. My hope is that this study may be seen as relevant and provoking.

5.19 Summary

This chapter has outlined the methodological basis of the study. The theoretical framework of social construction and analytical realism has been considered, alongside the methodological approach of ethnography used to explore the care and experience of care and illness of patients with advanced cancer. The process of analysing data has been detailed to allow the authenticity of the findings to be considered. Ethical issues, which arise when, an ethnographic approach is used in health research have been discussed. Having described the framework and process of the research, the next chapter describes the setting in which data collection took place.

6. Results I: Setting

6.1 Introduction

The study required undertaking a lengthy period of observation of experience and interactions of patients, families and clinical staff within a Greek oncology hospital setting. The physical layout, ward environment, and activities which take place near to where patients are treated and cared for can all influence the patient experience. Therefore, this chapter aims to describe the context in which the study was conducted. It describes the settings in which data were collected and provides a description of the context where patients' experiences and health professionals' attitudes and behaviours were shaped.

Fieldwork took place mainly in two medical wards (which have been named Ward Mariza and Ward Rallou) and a day care clinic of an oncology hospital in Greece. Some field notes and interviews took place in the admissions office, the canteen and front yard of the hospital, the emergency room of two other general hospitals, the cardiac clinic of another general hospital, a microbiology lab, the corridors outside of radiotherapy and X-Ray units of the hospital, patients' homes and two private health centres. I now present the three main places where data collection took place while details of the other areas will be given alongside the relevant findings, when necessary.

6.2 The hospital

The principal venue for data collection was a public oncology hospital in the centre of Athens. I chose this hospital for data collection following the suggestion from colleagues at the hospital where I worked and the president of the National Nursing Association who supported the view that it had expertise in cancer treatment and accepted patients not only from Athens, but also from all over Greece.

You should go to X Hospital, because it is one of the largest hospitals with expertise in cancer care and accepts patients not only from Athens but from all

over Greece because it covers most of the cancer specialties but also because it is the most advanced and updated one. (Nurse Director of a general hospital, audio 103, September 2005)

A reputation for expertise was confirmed by the patients. Some had come from a rural area and travelled a considerable distance to reach the hospital. Others had preferred this hospital to a private one, with better facilities, even though they were quite affluent, due to a belief they would get expert medical care in this particular setting.

D: why did you come here, so far from home?

S: Because here are the best doctors. ... We asked many people when we found out about my problem, and they all suggested we should come here because it is the best hospital. So, we thought it would be better to suffer from moving places and move the family here, in order to get the best doctors. (Sotos, interview data, audio 10118, 1 month before death)

Sometimes I think I should have gone to the X hospital [private hospital] ..., But I stay here because I trust the doctors.... (Pablo, interview data, audio 10173, 3 months before death)

The hospital has 350 beds available to patients with all type of cancers. The beds are shared among several specialties (referred to as clinics in the Greek healthcare system): two medical oncology clinics, a haematology clinic, a gastroenterology clinic, and a neurology clinic. In addition, some oncology-surgical specialties are offered. These are allocated to other wards: general surgery; orthopaedic and plastic surgery, gynaecology, and neurosurgery. A transplant unit and an intensive care unit cover the special needs of these groups of patients. A day care clinic covers the need for interventions for the outpatients. Most patients, once they become a patient of the hospital, remain so until their death, which also usually occurs at the hospital. The average number of patients who

died in the hospital in each of the past three years [2004-06] was approximately 520 patients.

The hospital was built in two phases - the building was constructed in the early 1960s but was later expanded in the 1980s. It comprises two wings - the west and the east. The west wing - built in the early 1960s - looks old the walls look dirty, and it has not had the benefit of renovation. The corridors feel quite narrow, and it is difficult for two stretchers to pass each other. I observed several times people being asked to move aside in order for wheelchairs to take priority. When I first arrived, it looked dark, and some areas smelt damp and cold, making it seem “musty”, despite the high ceilings. The old wooden narrow but nonetheless tall windows allow the noise from the street to come inside but also cannot preserve the heat generated by the radiators, something which some patients complained about.

I really do not want to go to ward Rallou [west wing]; it is so depressing. You cannot even open the window to get fresh air because it is already so cold and all the noise from the street comes in. (Natasha, interview data, audio 1023, 20 days before death)

In contrast, the east wing - built in the 1980s - looks modern, spacey and bright. It has big double-glazed windows and bright colours on the walls. Signs on the walls and doors help people to navigate their way around. Light comes from big windows placed on both sides of the corridors. Six large lifts to the sides of the main entrance facilitate patients, family and staff reaching their destinations. This contrasts with the west wing, where I often observed a queue of people waiting for the two lifts.

On the ground floor of the east wing, next to the lifts, there is a canteen for patients and staff. It expands to a near open plan area which functions as a coffee area with some tables and chairs facing the front yard. The front yard is located between the two wings and consists of some benches and flower beds, as well as a small garden at one corner near the

street where there is a chapel. A driveway for ambulances bisects the yard and some patients complained they did not feel safe, especially those who were unable to walk fast or needed assistance.

The only place I can go and sit outside of the ward is the front yard and the coffee place, but I need to smoke, so the only place left for me is the front yard. But I need someone to help me as my feet are so weak. And on top of that, you have the ambulances crossing and the car, which bring patients in, blocking everything. (John, interview data, audio 10007, 4 months before death)

Another difficulty for patients and staff members was the lack of parking facilities. Therefore, when patients visited the hospital, they had to find a parking space in the streets around the hospital, which were extremely busy and often full. Patients often used taxis or asked relatives to bring them to hospital because of this problem.

Sila was brought to hospital by her sister and brother-in-law. Her sister assisted her in the hospital while the brother-in-law waited in the car as there are no parking spaces available around the hospital... So every time Sila has to come to the hospital, she needs two people with her. (Sila's visit to day care clinic, field notes, September 2006)

6.3 Ward Mariza

The nurse director of the hospital with whom I discussed the study, encouraged me to situate my fieldwork on ward Mariza, with the argument that it was the main medical ward, receiving patients at all stages of their illness. Ward Mariza was based on the east wing, and, therefore, had better facilities than other wards; but most importantly, the nursing staff of the ward was open to people who wanted to do research. Later on, the nurses of the ward explained to me that the masters' students of the Nursing School often went to their ward for data collection.

Because ward Mariza was situated on the east wing, it felt new, bright and airy. The ward expands in the shape of an angle, and two lifts take people to its entrance. It was a 33 bedded, mixed sex ward. Patients of three consultants (oncology, gastroenterology, and haematology) occupied the beds on this ward, although 65% of patients were under the oncology consultant.

One of the first things that struck me about ward Mariza was how noisy it was. There were a lot of people having conversations and discussions in the corridors or asking for information. There were many people entering and leaving the ward on a constant basis, making the area seem chaotic. For the first days on the ward, I was confused as to who were inpatients, outpatients or visitors. Later, I realised that the lack of signposting at the entrance, the many doctors' offices outside the ward, and a haematology laboratory right opposite the nursing desk were some of the reasons for the noise and seemingly chaotic atmosphere.

'As if we do not have enough work, we need to do the secretaries' job too. At least half of people's questions are irrelevant to our ward. They want this doctor or the other, or even though they are for us, they come to ask if they are in the right ward. A notice outside would have helped so much, but it is still under construction... It is so distracting and frustrating. We end up being rude to the poor people. (Lea, nurses' discussion, audio 1083, 2 months of fieldwork)

Today I realised why the entrance is getting so busy and blocked. The haematology lab opposite the nursing office accepts its outpatients for their weekly routine blood tests, and there is not any waiting room, so patients and their carers have to wait outside at the corridor blocking the entrance of the ward. Doctors, who have their round at that time, seem frustrated from the noise and often ask people to move out of the ward. (Ward Mariza, field notes, 20 days of fieldwork)

The ward consists of 10 patients' rooms, the offices of the haematology and oncology consultants, a haematology laboratory and a nursing office and desk. The nursing desk located right after the entrance functions as the ward reception (Picture 6-1).

In the ward Mariza, the patients' rooms are quite spacious. Most have four beds, two on each side and an ensuite bathroom, shared by all patients of the room. The beds are spaced well apart, and the rooms do not seem cluttered. They have big windows, which allow a lot of light in. However, due to the heat in the Greek summer, patients often choose to close the curtains, sacrificing light for coolness.

Picture 6-1: Ward Mariza floor plan



The treatments provided in ward Mariza varied from the most aggressive anti-cancer treatment to end-of-life care, but consisted mostly of chemotherapy, radiotherapy and symptom control. As the cancer treatment is most often lengthy, many of the patients were frequently re-admitted, though it was not certain if they were going to be admitted to the same ward each time. The length of admissions varied from one night to three weeks,

depending on the patient's condition and stage. The age range of patients admitted to this ward varied from 18 to 50 years, with only a few patients over the age of 60.

6.4 Ward Rallou

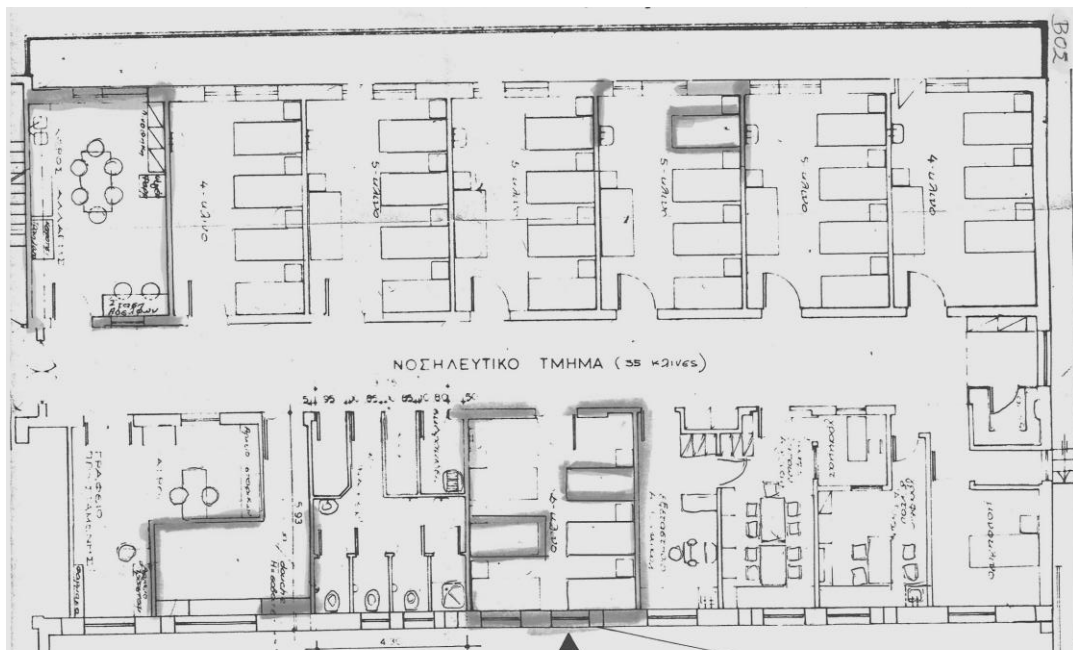
Ward Rallou was situated in the west wing - the old wing of the hospital. Hence, it looked old and dark as one entered. There was no indication of the name of the ward at the entrance, and I observed several times the nurses helping people with directions when they came in to ask. Nevertheless, I noticed from the first day that this ward was much quieter than ward Mariza as there were only a few relatives in the corridors and no outpatients looking for doctors. Perhaps this was related to the fact that there were no doctors' offices on the ward apart from the gynaecology consultant, and also no other offices in the vicinity of the entrance to the ward.

Ward Rallou was smaller than ward Mariza. It was a 21 bedded (7 patient rooms), mixed sex ward (Picture 6-2). The beds were allocated to the same consultants as ward Mariza - with the addition of the gynaecology consultant - by the admissions office. The nursing office and the sister's office stood opposite each other, right after the entrance while the patients' rooms were on both sides of the ward's corridor. While being on the ward, I found it difficult to attend to the rooms at the back of the corridor. The rooms were situated along the entire length. Nurses also expressed difficulty in monitoring patients in the distant rooms and often requested relatives to approach the nursing office if patients in these rooms needed something.

If it is to check for the patients, I have to walk up and down the corridor all the time, I cannot do that. I cannot hear or see what is happening at the rooms x and z, that is why we try to have the more ill patients near to the office. ... families have to help us and come here to tell us what they need, rather than just ring the room's bell. I keep telling them. (Nelly nurse, interview data, audio 101165, 10 months of fieldwork)

Unlike ward Mariza, the rooms in ward Rallou felt cluttered despite the big windows. This was because they were smaller and the four beds were very close to each other. A chair could hardly fit between the beds. Nevertheless, the rooms on the left-hand side of the corridor were quite bright, though very noisy as they faced the avenue. The rooms on the right-hand side were quite dark as their windows faced the wall of another building. These rooms could also become quite noisy, sometimes at night, as the trolley path for the hospital was just outside.

Picture 6-2: Ward Rallou floor plan



Ward Rallou did not have ensuite bathrooms in the patients' rooms; instead there were two extra rooms, one with three toilets and one with three showers. The toilets were not easily accessible for patients as there was a step up from the corridor. Some patients complained it was difficult to access them, especially those with fatigue.

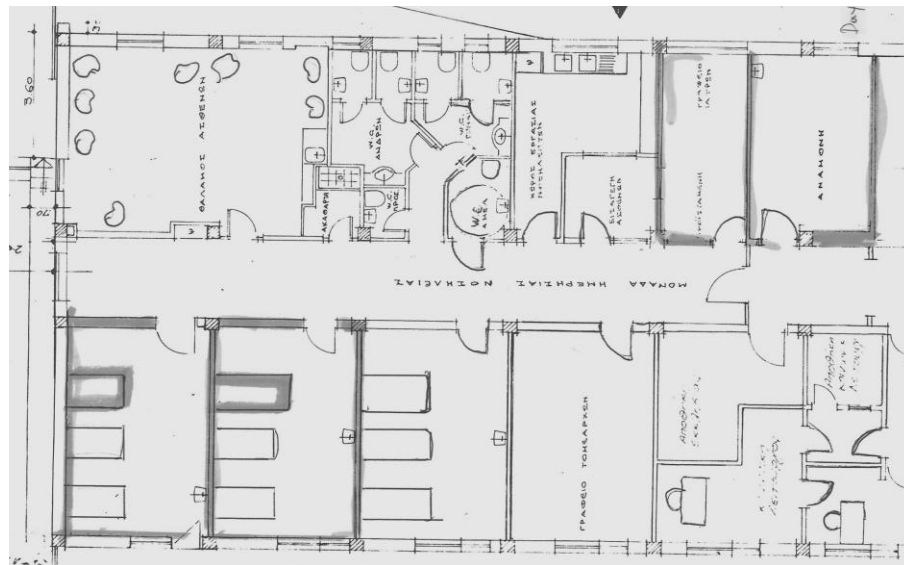
I don't want to be on this drip because then I need to go often to the loo, and I cannot. As if it is not already difficult to walk, I have to climb this big step; I really don't have the energy for this. When my mum and dad are here, they practically lift me up. Who thought of making toilets as such? It is for patients'

access, for goodness sake. (Natasha, interview data, audio 10193, 20 days before death)

Patients on this ward seemed to be older and receiving less aggressive treatment. I did not observe many patients receiving chemotherapy or radiotherapy. Instead, most were under symptom management, or treatment for side effects and complications, such as dehydration, uncontrolled pain, and cachexia. Effectively, many of the patients in ward Rallou were at the end stage of their lives. The length of admission varied from one or two weeks to three months, depending on the patient's condition, stage and family support system. The age of patients admitted to this ward varied from 45 to 78 years, with only a few patients being under 40.

6.5 Day care clinic

The day care clinic was developed in 2004. It is situated in the ground floor of the hospital, at the back of the old wing (Picture 6-3). The entrance door is usually kept closed, and there is a plate with the name of the clinic on. The clinic consists of an open plan ward with beds on one side and comfortable leather armchairs on the other side. It has 12 beds and 12 chairs. Because it was recently developed, it looks quite new, with modern decoration and furniture. The doctors' office and the nurses' office are situated next to the entrance door while the toilets stand in the middle of the ward.

Picture 6-3: Day care clinic floor plan

The patients' waiting room of the day centre clinic is situated outside of the entrance to the right. It is a small room with approximately 20 chairs. Complimentary coffee, tea and cookies, are offered to the patients waiting by the social service, on a voluntary basis. Waiting was difficult for patients as it was sometimes more than two hours. Patients had to wait outside until they were called in. There were several occasions I observed patients lose their patience, and try to enter uninvited. By the end of the data collection period, a security guard was appointed to the day care clinic's entrance door, in an attempt to keep relatives and patients outside the clinic until a space was available.

The clinic accepted all patients who were treated in the hospital. Medical treatments included chemotherapy, blood transfusion, interventions such as drainage of ascites, and routine blood tests. Also, emergencies that did not require admission were dealt with in the day care clinic. If patients had an appointment with their doctor, they visited them in their offices or the outpatient clinic.

Appointments at the day care clinic were regulated by the admissions office. A written request by the consultant was handed to the patient/family, which in turn had to submit to the admissions office in order for appointments to be scheduled. On some occasions, two patients forgot to submit the note with the consultant's request and missed appointments as arrangements had to be planned at least a week in advance.

We forgot to give this little paper to the admissions the other time, and now we cannot get in the day care clinic for his chemotherapy. They said they need to reschedule, which means that the chemo will be delayed for at least a week. With all the things we need to do every time, I forgot about this stupid thing, and now I feel stupid, and Giorgos is angry with me. (Iris - spouse of a patient, interview data, audio 101134, 43 days before death)

6.6 Participants

In total, 93 participants took part in the study: 13 patients, 34 family members, and 45 health professionals involved in patients' care (Tables 6-1 and 6-2).

Table 6-1: Patients and families - participants in the study

Patient (age)	Place in the family	Family carers	Others
Con (30)	Son	Mother, father and brother	Aunt (20 days before death)
Natasha (37)	Daughter	Mother and father	-
Maria (40)	Spouse	Husband and sister	-
Giorgos (41)	Spouse	Wife and mother	-
Pablo (50)	Spouse	Wife and daughter	Two siblings of his wife
Ursula (53)	Single	-	Two friends occasionally
Kula (57)	Spouse	Sister and husband	Niece
John (60)	Divorced	-	Neighbour sometimes
Tamara (65)	Mother	Three children and husband	-
Sila (67)	Spouse	Sister	Niece
Mina (70)	Widow	Sister	-
Sotos (72)	Spouse	Wife and three children	Friend
Fritos (70)	Spouse	Wife	Friend/neighbour

The health professionals group consisted of the chief executive of the hospital (doctor); the nurse director; one psychiatrist; one social worker; 15 doctors and 21 nurses (Table 6-2).

Table 6-2: Health professionals - participants in the study

Chief executive of the hospital	1	
Nurse director	1	
Psychiatrist	1	
Social worker	1	
Doctors	3 Consultants	Ward Mariza
	3 Registrars	
	4 House officers	
	2 Consultants	Ward Rallou
Nurses	1 Registrar	
	2 House officers	
	The Sister	Ward Mariza
	11 Staff nurses	
	The Sister	Ward Rallou
	5 Staff nurses	
	The Sister	Day care clinic
	2 Staff nurses	

6.7 Summary

In this chapter, I have presented the places where this observational study took place, over a period of 25 months, with the aim of situating the study in its context. I described the hospital chosen for data collection and the three main wards where I followed most of the participants during their last months of life. Some quotes from patients and nurses in relation to the specific setting have also been included, with the intention to provide elements of their experience of working, or being cared for, in those settings. It is against this background that I will now present the experience of doctors and nurses, families, and patients as reflected in the data collected, and the observations made during the study.

7. Results II: Culture of care

7.1 Introduction

This chapter presents findings related to the nature of care offered to patients involved in this study. It explores the attitudes and beliefs of doctors in relation to dying and death as well as their role in decision-making. Nurses' views and those of other health professionals are also presented.

This chapter has three sections. The first, 7.2, describes the culture of the hospital in relation to the culture of care and explores three main features; fighting for cure; biomedical model; bureaucratic elephant. The second, 7.3, explores the beliefs and attitudes of doctors who looked after the study patients. A framework is offered to explain the dominant attitude of fighting for cure until the end of life, focusing on three domains: doctors' personal attitudes towards death and dying; their relationship with patients and their expectations of the families. In the third, 7.4, nurses' views about their role in the patients' care and their involvement in decisions about care are analysed.

7.2 Hospital culture

7.2.1 Fighting death until the last minute

The orientation of the culture of the hospital started revealing itself when meeting with key gatekeepers during my first attempts to enter the hospital. Comments and suggestions provided to me by the nurse and medical director during our first meetings to discuss the study proposal suggested a focus on treatment and cure. The terms palliative care, terminally ill patients and expectancy of life or prognosis were not welcomed because they were not in tandem with the hospital culture. Senior staff thought that palliative care is a way of giving up the fight. Those suggestions made me think that the subject of the study might conflict with the goals of the hospital.

The nurse director told me today that she was not happy with the wording of my proposal. She said that this hospital does not consider any patient terminally ill. She also said that the hospital is determined to fight for saving a person's life and a project like this would not fit with the principles of the hospital. (Field notes, meeting with the nurse director; first week of fieldwork)

He [chief executive] said that he was not happy with the words 'expectancy of life'. He explained that the attitude of the hospital is to fight until the very end; and that they do not speak about expectancy of life, as nobody can possibly know, but only God. He said that palliative care is a way of giving up on people; even if cure is not possible, prolonging life even if for one more day, is valuable. (Field notes, meeting with the chief executive; first week of fieldwork)

Similarly, the ethics committee of the hospital expressed their concerns in relation to this study and the goals of the hospital. In order to approve the study, they requested the revision of terms relevant to terminal illness. Instead of patients with terminal illness or patients with expectancy of life of six months or fewer, I had to use terms of patients with metastatic cancer or patients with malignancies in advanced stage; terms which are related to diagnosis rather than prognosis. All together it took me four months to convince the key people, obtain access and permission to undertake this study.

7.2.2 Fragmented services: 'A fragmented elephant'

Doctors, nurses, the social worker, patients and families spoke about the problems bureaucracy caused to the delivery of care and the everyday life of patients. The lack of co-ordination of services in the health care system but also the fragmented services existent within the hospital organisation seemed to delay treatment and care for patients and encourage families and health professionals to manipulate the system for the benefit of patients.

Effect of insurance/ payment system: 'Negotiating the health labyrinth'

As most patients were insured by one of three state insurance policies, their treatment and care had to be approved by their insurer. Consequently all their medication, interventions, surgical operations, admissions to the hospital had to be approved by their insurance provider. However, the way the hospital payment system was set up meant that these arrangements could not be made in the hospital. Therefore, the patients or their families had to physically travel to the relevant insurance providers' offices to receive approval, receive relevant receipts to cover expenses and to get authorisation stamps on prescriptions to receive their medication.

A simple example, we give a prescription for erythropoietin to a person with TEVE insurance. The patient takes the prescription and then starts an obstacle race. First he must go to a TEVE doctor where he lives, he gets the drug prescribed, then he goes to the local TEVE offices, they get the drug approved then he comes back to the hospital pharmacy to get the drug... A local pharmacy would not be allowed to dispense it. So this person loses one workday? Doesn't he have to be absolutely healthy to do that? Can a cancer patient who is sick and in pain do that?" (Dr. B, interview 2, 11881)

Communication across the health care system

The health care system services had no structure of communication. If a patient was transferred to another hospital or referred to a specialist in another setting, the patient and the family had to collect all the relevant medical documents and transfer them to the new place. Patient Ursula is an example of the situation. She was sent to a general hospital, to be seen by a cardiology clinic, and she had to take with her all the relevant medical documents from the oncology hospital for the cardiologists to review. In the end, she brought back to the oncologist the test results and recommendations of the cardiologists.

Similarly, patients or their carers had to transfer documents within the hospital in order to arrange appointments, interventions etc. When a patient did not have family around to support this process, then the social service would be called to help. Where families were confused, the patient could miss his turn for the next admission for treatment, miss an appointment, or blood test results could be lost.

When my husband was admitted for the first time, I had to go to seven different desks in the hospital, queue up, get a ticket, queue up there and go to six other places and then go back to the same place, get another ticket and stand. It took over two hours. I was well, I was fine but I began to feel much stressed. ...There was a man next to me, an old man. He was just foaming. He didn't know where to go. He was up to here. He had no one to help him and I thought if patients are on their own and they are not feeling well, how do they manage? (Jella, Pablo' wife, audio 12390)

...Iris explained that they could not be admitted as she should have arranged this appointment with the administration the last time they had been in. She was been given a short paper, with the date the doctor suggestion for next admission which she should have given to the administration in order to get the appointment. She said she was desperate, as she had not been explained so and now the chemo would be delayed... (Field notes, Giorgos data; 4 months before death)

There were times when nurses offered support with some of the paperwork on behalf of the patient to release some of their burden and stress in handling administration. This was especially evident if the patient was well known and had been treated for a long period in the hospital.

'The people in administration and management have no knowledge about the distinctiveness of an oncology hospital. There is no knowledge about what it

means to be an oncology, often chronic patient; what it means to provide sensitive care to patients who will die'. (Nurse Eleni, audio11093)

I am going down to arrange Antonis' CT scan [an advanced stage patient,]... well, obviously he cannot do it himself and his mum is completely exhausted. How can they expect him to arrange all this? It's ok, I will be back soon. (Nurse Rena; audio 10120)

Delay in delivering medical service

The services within the hospital lacked communication and co- ordination with each other. Every unit had its own rules and pace of work, which often resulted in patients having to wait for periods of several weeks until diagnosis was made or a treatment offered. To give some examples, the admission office rigidly followed lists for admitting patients and was not flexible in responding to emergencies or the importance of individual cases. Similar issues occurred with the operating theatre, the pathology lab, and the radiology unit. Also, as the health professionals suggested, there was no infrastructure for effective communication between departments and specialties, which resulted in delays of weeks to patients' care; health professionals regularly had to rely on their personal good relationships in order to push a procedure faster.

The following quote by an oncology consultant vividly illustrates the inflexible, solid system of the hospital, by using the metaphor of an elephant:

What I want to say about all that is that the State and this hospital is an elephant, which squishes everyone under. And it's an elephant not because it's individual workers are elephants, it's because the system is structured in such a way, it moves so slowly...it's a picture of a pachyderm, a picture of indifference... everything is dealt under a certain set of rules, and it is not adjusted to the needs of the specific occasion. (Dr A; interview1; audio 1029)

Partly because of the indifference and not proper behaviour, bad attitude of some directors and employees in some departments, the biopsy results may take 45 days to 2 months. (Dr. B; audio 10346)

...The patient is admitted for 5 days and nothing is done. He gets a blood test one day, then for 2-3 days he may get nothing waiting for the results. Then another waiting for another test ... It has been a week and the patient is in there; waiting. (Nurse Effie, audio 1029)

According to many of the health professionals, the administrative managers could not improve the situation as they were not familiar with the particular features of an oncology hospital and the specific needs of this group of patients. They believed that the hospital managers treated the service as any other acute care hospital, without considering the unique nature of the chronic nature of cancer care and the specific needs of this particular group of patients. They also said that such an indifference of the system and the bureaucratic inflexible organisation of the hospital had the outcome of demoralising the health professionals, who often stated that they felt hopeless in influencing care provision for the benefit of patients.

Administration doesn't understand the sense of "quality assurance" or that... they have been appointed here to lower the deficits, they haven't been placed here to improve the quality of services that are provided. They don't understand what it means to be running an oncology hospital nor do they understand what it means to treat cancer patients in a humane and dignified way. It is not because they are bad people. They just don't know this; it's not something they are familiar with. (Dr. Bonus, interview 1; audio1076)

The system does not consider me a thinking person. To the system, I am a public employee, and I have to do what I have to do with nothing else. I can't influence things in a positive or negative way. In a positive way I can work

harder and in a negative way I cannot work. ... I will do what I can, but I will need to survive as well. (Dr Math, audio 1022)

Physicians tried to overcome the system by keeping patients longer in the hospital until they could secure the relevant test results, although patients did not necessarily need to stay in. In this way, they could bypass the long queues for tests, scans and other interventions for outpatients. Sometimes doctors provided patients with a leave of absence off the record until the test results would come and then be able to move on to the next procedure. Otherwise, they would have to queue for every test and, therefore, start treatment much later. However, this resulted in extending the queues for other patients' admissions.

You admit a patient for chemotherapy which lasts three days but cannot be done in the Short Term Unit... And in order to decide for his [patient] treatment, this patient must get a CT scan. He waits for a week because it's not his turn yet for a CT- scan. It's not his turn for whatever test. But if the patient is discharged, then he gets moved to the end of the list. (Dr. Art, audio10110)

Con has been delayed his cycle of chemo for almost a week now. I saw his father today outside of the admissions office. There are no available beds; Con lost his turn to be admitted some days ago and now he is at the end of the list. ... There are four beds empty in the ward Mariza but the admissions office is not informed, as these patients are absent with the agreement of the doctors, but off the records. (Field notes, Con data; 15 days before death)

7.2.3 Pervasiveness of biomedical model

The services of the hospital were organised around the treatment of the disease. It included several medical, surgical oncology clinics, and radiation specialist unit while the psycho-social services were understaffed. The patient care was focused in the treatment provision whilst less attention was given to the quality of life

Nature of care: focus on cancer treatment

The care discussions and plans were organised around diagnosis, progression of the disease, metastases, effectiveness of treatment, symptoms or side effects that obstructed treatment delivery, and different treatment options. My observations of medical meetings and ward rounds included notes related to cancer state, screening test results, blood tests, aggressive treatment or options of more treatment. It also included communication with other specialties and different labs in relation to multimodality treatment; (such as surgical, or radiation), dealing with complication of the disease (such as fractures and stomas). They also addressed physical symptoms, which interfere with, tolerance to treatment modalities (such as nausea-vomiting, dehydration, anaemia).

I decided to follow the medical round today. The consultant x came around 10.00, and we started from room 1501. All relatives were removed from the rooms in order for the doctors to see the patients. Whilst standing around the patient bed, a house officer updated with the patient situation. The communication was around tests results, treatment provision, arranged appointments and guidelines were given by the consultant on how to proceed with more tests results, treatment modalities, plan for discharge, and referrals to other specialties. They rarely spoke to the patient, and they used all medical jargon and abbreviations. A few patients said they had some questions, but the doctors said later, as they had to move on to the other patients. In the end, three patients asked me what the doctors had said, as they could not understand what was said. (Field notes, medical round, morning shift- ward Mariza, 5 months of fieldwork)

The patient notes included pages for reporting history of disease entitled as medical history, a chart for vital signs and other bodily measurements, space for the prescribed medical treatment entitled as medical orders, a section for the planned tests, and a section for their results. The recorded tests specified cancer recurrence, defined cancer

stage, and assessed the effectiveness of treatment on cancer. Plans of care included treatment plans; follow up meetings, scheduled of screening tests, and monitoring blood tests.

The daily nursing notes which covered the 24hour shifts mostly confirmed that treatments had been administered, and medical guidelines had been followed. Symptoms were reported occasionally, without specifying intensity and were not followed up. Those symptoms reported were mostly related to side effects- tolerance of treatment which would influence the course of treatment, such as fever and nausea. Breathlessness was recorded only in acute crisis (e.g. patient on oxygen, dyspnoea event). Description of pain, location, intensity was not recorded and not routinely assessed by the health professionals. Pain was documented only if an action was taken (medication provided), without the outcome of the intervention.

Following the medical and nursing notes, I did not find any psycho- social or spiritual assessments, or functional status. There were no notes addressing elements of quality of life, family status, carers' issues, or a section about patient's needs, patients and families' preferences, choices. The only records of psychological issues were three cases where the psychiatrist was called. In two cases, anxiety medication was prescribed to deal with a patient's panic attacks when she started thinking that she might die, and another patient's refusal to continue with treatment; in the third occasion, antidepressants were suggested to a patient who refused treatment and expressed suicidal thoughts.

Strict opioids policy

The priority to treatment and not symptom control can be verified by the government policies in relation to pain management. Although pain is accepted as one of the principal symptoms related to some cancers, its management seems not to have received enough attention from the health care system. The policy for prescription of opioids by the Ministry of Health was restrictive, making difficult for patients to receive adequate pain

management outside of the hospital and caused problems for patients and their families. According to this policy, an opioids' prescription should cover the patient for no more than five days. Only a few pharmacies were allowed to provide the relevant opioids, usually those located around a hospital. In this way, the Ministry of Health could control the possibility of misuse or misconduct. However, that meant that the patient or a family member should visit their doctor in the hospital every five days to renew the prescription, and after that go to the relevant insurance office to get the stamp of approval and finally chose one of the specific pharmacies to get the medication.

Health professionals and families and patients tried to overcome this problem by employing different strategies, according to the circumstances and nature of relationship that had developed. John, a patient who had no family and needed opioids for pain relief paid a neighbour to help him with this procedure every five days. In the case of Sila, her doctor prescribed at least double doses so that she could get enough medication for at least ten days. In the case of Kula, she was kept in hospital for the last three weeks until her death, in order to be able to receive enough morphine for pain relief. Dr A. explained the situation clearly:

The prescription [of morphine] is for every 5 days. And we're talking about people who are probably completely incapable of moving... if you get the possibility of providing them with morphine for a whole month, or at least 20 consecutive days, it would let them stay in their home. And if it's a stage just before death or close to death and they are entitled to this morphine, they can really manage to stay home. But if this patient doesn't have any relatives, this person, according to those high and mighty legislators responsible for these circulars,..., must be here every five days. Imagine the monstrosity of that.... These people have only two options. They will either bring someone of their own who they may have to pay very handsomely ... who will be coming to collect the prescription every five days according to what those gentleman

want. Or the doctor feeling the magnitude of the tragedy for these people will admit them in the hospital. ... Or the doctor will have to prescribe a false prescription for a larger dose. (Dr. A, audio 10345)

Psycho-social services

The whole hospital (of 350 beds) was covered by one psychiatrist responsible for the needs of patients, families and perhaps of the health professionals. One psychologist who had worked in the hospital had left two years ago and had not been replaced. The explanation given to me was that the hospital board thought that a psychiatrist position was adequate to cover for the patients' psychological issues. Although doctors stated that they needed more people in the psycho-social services, it seemed that they were not clear as to the value and role of those services. Doctors seem to consider those services as supportive to their work when an obstacle had occurred [e.g. a patient refused treatment] and not on a regular basis, to provide psychological assessment and support for patients.

... They [psycho-social professionals] are needed when we deal with a problem patient. When the doctors feel that they cannot manage with a patient who for example has rebelled and refuses treatment or misbehaving, or when the patient had social problems but needed to be discharged. (Dr. Antony; audio 1230)

Only the oncologists could refer a patient to the psychiatrist. Other health professionals were not considered eligible to refer patients for psychological support or treatment; instead they could make a suggestion only to the relevant doctor. However, there were occasions where family members had visited him in his office asking for help, with the result of him liaising with the patient's doctors.

What I'm trying to tell you is that it's not about who needs it [psychological support], but who is eventually referred to me... but I manage though, those

who come directly here [office]. But you understand that one person is not enough. (Psychiatrist Interview 1; audio 10247)

The psychiatrist seemed to be called when a patient developed a disorder in behaviour and not usually for psychological support. Doctors explained they referred patients to the psychiatrist when the patient was ‘*out of order*’ [i.e they were perceived to be difficult rather than just in need of help] and did not comply with patient advice or treatment choices. So, the aim of the referral was to aim to get the patient to comply with the requirements of treatment. The psychiatrist confirmed this practice, suggesting that patients were referred to him too late.

When the patient refuses the treatment, then I call the psychiatrist to help make the patient comply. ... Because they are depressed or have other problems they stop obeying, and thus we ask the help of psychiatrist to put patients back on track. (Dr B; consultant, interview 1; 1076)

Social services in the hospital were one social worker and occasional support from a few students who were doing their placement training. Whilst a formal referral was done for the psychiatrist, the social worker was called simply with a phone call and asked to visit the specific patient. No formal procedure was in place and thus there are no formal referral records of the social service demand. Both doctors and nurses could request the help of the social worker. The social worker stated that the demand was much higher than what the service could offer; but she thought that health care system did not value the social service’s importance.

There are always long queues outside of my office; it is only me as a professional and a team of volunteers. Thankfully they send students for training here so, I usually have one or two of them helping out; but ... as soon as they learn the work, they have to go. I keep asking for more ... The ministry of health is not interested in. (Social worker, audio 12303)

The social worker had managed to develop a network of volunteers in order to ensure they were able to mount a response to the countless problems patients faced. Often the volunteers visited the wards with the aim to identify cases that they would benefit from the service.

Neither the social worker nor the psychiatrist were invited to address the psychosocial needs of the patients, but instead served to ease the way for doctors or the administration. The psychiatrist and the social worker were often called when doctors needed a bed that was occupied by a patient who had nowhere to go, or was not able to pay the hospital fees and thus could not be discharged.

She [a patient] was admitted thinking that she was dying but now she is stabilised and they [doctors] want to discharge her; they need the bed they said ... she is alone, no family environment and thus she is called 'the social problem patient'. Although nurses flagged up the issue a week ago, the social services were only called just now that they need the bed. It was explained to me that the social worker will need to find a place for her to go, and somehow her expenses to be covered as she has no insurance (Field notes, evening shift; ward Rallou).

Implementing a strategy to tackle the problems the psycho-social services were facing, seemed not possible at the time. The lack of staff resulted in acute work overload for the two staff members. They delivered care in response to the day to day demand. They argued they could not plan, and felt helpless due to lack of support and collaboration with the other professionals.

I cannot plan or organise the work. The work is huge; I cannot solve the problems, so I am just acting on a first come first served basis. Managing the day often seems a miracle. (Social worker, interview 2; audio 1047)

Power of the medical profession

Hospital care was organised in a hierarchical structure, which was determined by the medical profession, e.g. the medical director. A perception of hierarchy of knowledge seemed to exist, which placed physicians as the heads of teams of health professionals with the other occupations and professions within the team under their authority. This was evident by the way decision-making were made about patients' care and treatment; Doctors assumed full responsibility over patients' care decisions which were not shared between the other groups of health professionals. Doctors stated that they held most of the knowledge and thus could determine patient care.

Of course the system works hierarchical. It is the medical director, the consultants, then registrars to house officers, then the sisters of the wards and then the nurses. This is right, as we have more knowledge than the other health professionals. We can do your work, but you cannot do ours. (Dr. M, registrar; audio 1380)

Doctors confirmed that patients' treatment and care was their responsibility and that the other health professionals had a supportive role. Dr Bonus when asked about nurses' contribution in particular, he seemed to rather equate nurses' contribution to technical aspects of care/ advanced practice rather than a more holistic view of what nurses bring to treatment and care, especially in the role of psychosocial care. He suggested that nurses should take more responsibility in the care delivery, rather than the decision-making.

Nurses' job is not to assess patients; it is to do their work. If they really want to improve their profession,...not only to clean the patients and change sheets ...they should do more and help with the work load; in other counties nurses have more skills; eg, they do ultra sounds etc. It is not about making the decisions; they should be more collaborative in this way. Otherwise, they'll end

up doing nothing but emptying bedpans. But that's easy because they just empty five bedpans and go home. And they have no responsibility. (Dr Bonus, consultant, interview 2; audio 11881)

This lack of participation in assessment and decision-making of care was confirmed by the psychiatrist, the nurses and the social worker. For example, nurses complained a few times that they thought they should refer a patient for psychological support, but they had first to convince the doctors, in order that a referral prescription could be made.

I keep telling him [patient's doctor], that Marios [a patient] is very distressed and needs support. He is not coping for the past month and he is keeping all his anger inside. How long have we been saying this? It was inevitable that he would blow up. Now they call the psychiatrist? ... But of course nobody listens to the nurses and we cannot refer patients ourselves. (Nurse Mary, morning shift; audio10444)

My observations confirmed this practice. There were no meetings between health professionals to discuss patients' cases, such as the multi- disciplinary meetings in the UK. The doctors would make a round every day, and then report their findings in the patients' files. Then the nurses would update the patients' drugs cards and follow the new medical orders. The social worker and the psychiatrist would come to the ward if there was a referral for a patient. So, the view of patients often proved to be fragmented, as health professionals did not often share information and opinions about patients and thus could not bring their own input or perspective on an individuals' plan of care. A few patients expressed their concerns about this.

... the knowledge of the team about me is fragmented. For example, different people come and ask about the same things and I have to repeat it over and over again. And that is the best scenario. The worse is when you talk about your problem and then someone else comes and does exactly the opposite from

what you would need, because he simply did not know. I say something to the nurse, and I expect that the doctor would know; or I tell something to the doctor and expect that the rest of the team who come to me should know. But they don't. (Pablo, audio 10574)

Doctors had power over patients' treatment options and place of care, without always taking on board patients' preferences. The patients' wishes were often not fulfilled if the doctors were not convinced that their preference was the best choice. When asked, doctors confirmed that decisions should be taken by the doctor for the patient. They supported their view based on two arguments. First, the patients were not aware of their situation and thus they were not in a position to make the right decision. Secondly, doctors had the knowledge to assess a medical situation and decide on the best way forward; patients should not be burdened with such decisions.

In medicine, there are products and services on one side, the customer on the other but the person who will make decisions for the customer is a third person, the doctor. We have to decide what's best for them, because we have the knowledge to do so ... When the patient knows nothing, he will say 'I want to go to my village'; but is this the right decision for him"?

During fieldwork, I had observed that patients were not informed always of their diagnosis but mostly of their prognosis. There were patients who knew that they were undergoing chemotherapy but had not realised that this was a treatment for cancer disease.

Nevertheless, doctors shared decisions with families, thus expression of a patients' voice relied on whether the family adopted an advocate role or a one where they supported doctors' opinions. This process was not often straight forward and conflicts often developed.

Some physicians seemed to be in a position to exercise power over hospital administration. They often tried to bypass the waiting lists and rules of the system with the aim of helping their patients. On more than one occasion, I observed two consultants managed to transfer their patients from ward Rallou to ward Mariza (a ward with better facilities) by making phone calls to administration when the admission office had previously reassured the patients' families that there were no beds on ward Mariza. Also, occasionally they managed to admit patients for treatment, or offer appointments for CT scans, despite the fact they were not at the top of the list/queue.

Natasha's father went today again to the admissions office trying to get a room in the ward Mariza for his daughter. Natasha cried that she could not stay anymore in that room [in the ward Rallou] packed with old dying patients. ... A nurse suggested him to go to Dr Bonus and ask for his help; otherwise he would not succeed to transfer her in the other ward. ...This evening she came back to the ward Mariza. (Field notes, ward Mariza; a month before Natasha's death)

...a woman with a bag on hand knocked on the door of the nursing office and said: Hello, I am Elsa Mainou. I came. Where should I go?

Nurse M: I am sorry, did we expect you? Do you have a submission card?

Patient: Well, this morning I got a phone call by my doctor to come. He gave me a preliminary card which he said that the admissions office will have to replace it tomorrow morning with the official one. (Field notes, Ward Mariza, afternoon shift)

The physicians who seemed to have power over rules and administration procedures were usually the top consultants, the clinics directors. Hence, patients' care depended on the specific consultants and the power that could exercise to the administration, to a certain extend. The fact that they could influence procedures and offer priority to their

patients raised concerns of equity to other patients and families. Patients who were not treated by those oncologists were not successful in bypassing the rules of the system with the result of enduring the long waiting lists and delays of treatment.

Did you see what happened with Pablo? We were together at the admissions office and his wife was told that there were no available beds, but she called their doctor and now Pablo is in. Our doctor is not keen to exercise pressure or maybe he does not like us that much and no bed has been found for Giorgos. We have to come back again. (Giorgos' wife, audio 12302)

Con' s chemo cycle is now delayed for almost a week, but they say there is no bed for him to get admitted. Dr X is abroad and she cannot help us this time. Con father will keep coming every day, hoping to secure a bed for Con the soonest possible. We are really worried as Dr X told us it is important to have the treatment on time. (Con' mother, audio 10300)

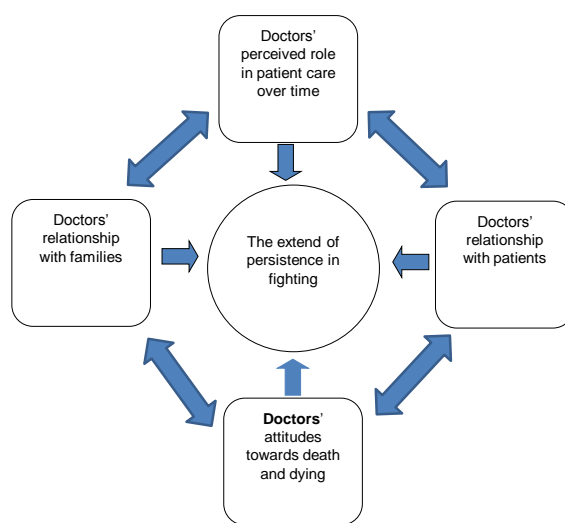
I experienced the power when I tried to receive ethical approval for my study from the hospital's ethics committee. There were no guidelines or application format for submitting a study protocol. I was not offered any criteria of what was expected, in order to be successful with my application. Instead I was told (off the record) that if I did not know doctors to support my case, I would not been given a chance. Indeed, my application was blocked twice before it reached the ethics committee. I managed to get through, when a head consultant- to whom I was introduced by a friend- helped me by arranging an appointment with the consultant – chair of the ethics committee. Then I was given the chance to present and defend my study.

7.3 Doctors views on death and dying and their role in the patients' care

Data showed that fighting for cure and persisting with and even intensifying aggressive treatment until close to death was the main attitude of doctors towards patient care.

Four parameters were identified to have an influential role in shaping the extent to which doctors persisted in and intensified fighting for cure: doctors' beliefs about their role in the treatment of cancer; doctors' attitudes towards death and dying; doctors' relationship with patients and with their families (Figure 7-1). The following section presents findings organised around these parameters.

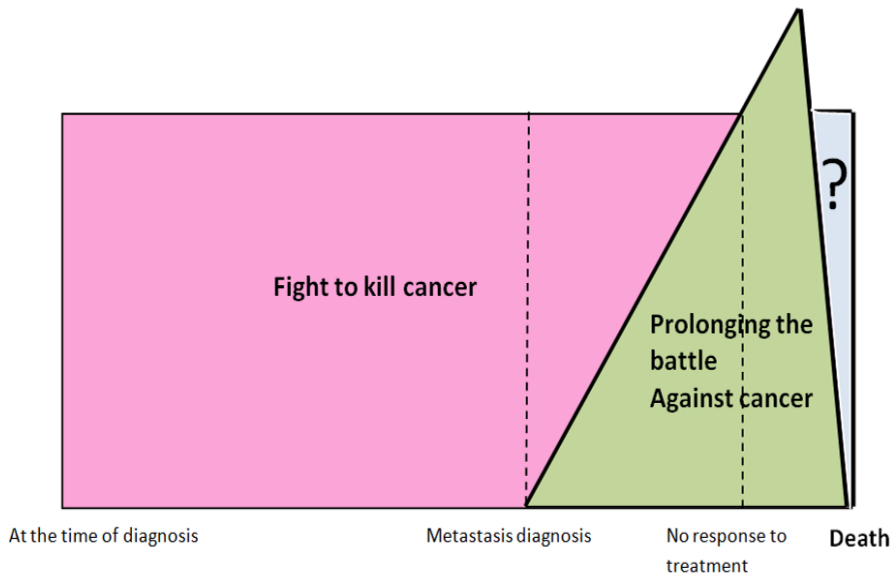
Figure 7-1: Factors influencing the extent to which doctors fight for cure



7.3.1 Doctors' perceived role in patient care over time

The doctors who cared for the study participants expressed the view that their role was to cure patients. However, this role was adapted over time as the disease progressed and the patient eventually deteriorated. Three stages were identified over time: fighting to defeat cancer; intensifying fight and prolonging the battle against cancer when metastasis is diagnosed and signs of no response to treatment appear; disappearing from the bedside during dying and death. (Figure 7-2)

Figure 7-2: Doctors' perceived role and choices over time



Fighting to defeat cancer/cure

Data revealed that fighting for cure until the end was an imperative, so that other choices near the end of life, such as where one might die, when to begin the process of farewells did not enter into the equation. Doctors often stated that their goal was to save people's life and cure them from their disease. Thus, all efforts were directed in defeating cancer.

I am an oncologist and my job is to defeat cancer, save people's life. (Dr Bonus, consultant)

I do everything I can to help the patient. I use science and my knowledge to save the patient, despite the fact that we haven't managed to cure every disease; or to contain every disease and stop it from spreading. But this is my role as a doctor. It is not a matter of what I want, but of what I have to do as a doctor. What is most important to me is that we should respect our roles and our work. (Dr Anton; registrar; audio 11827)

For some doctors, fighting cancer was perceived to be a personal challenge, not just their job. Dr Art, in most of his accounts, focused on the personal element of fight he had with cancer and death more rather than on specific patients' matters. He considered himself a brave fighter who was prepared to take risks during fight, e.g. trialling new drugs. He explained that he appreciated the constant challenge and that he chose oncology for the excitement of fight.

Oncology is for people who love challenges and fighting; what I call the battle and war with what is superior to you which is the evil disease and death ...I love battles; it keeps the adrenaline up every new challenge... I have to admit that what mostly keeps me alert and in this reality is this excitement I get when I'm waiting for the result of a trial... not necessarily a trial, an effort; the results of an effort; a new effort. It is one of the things that keep me alert. Ever since I was a child I had this thing, I would fall asleep... if I didn't have something going on that would interest me and excite me... It is like extreme sports. (Dr Art, 1st interview; audio 1029)

Other doctors reported that the attitude of fighting for cure was a measure of their success as doctors. Dr Bonus explained that beating death would be a proof of his abilities as a good doctor. When successful he was in a position to appraise himself, whilst when patient died, he had to face his limitations and remain humble.

It's a great lesson to me though, so I will stop praising myself and thinking that I can cure them. (Dr Bonus, audio)

Cure no more certain: Aggressive treatment intensified

When a metastasis was diagnosed, doctors said that they received the first sign of losing the battle, and thus failing in their role. Such development led them to intensify their efforts of fighting for cure, hoping to put the disease back into remission. Different treatments were trialled, new treatment developments were explored and more

treatments combinations were offered (e.g. chemotherapy and radiotherapy together). The treatment sessions became more intense in an effort to control cancer, whilst gaining more time.

...you know when a patient has his first relapse, his first important relapse which you know that it is incurable. E.g. when the disease spreads to the brain that is when it is sealed and you know that the end is near. And it is usually close. And what matters is not the flexible part about the end; whether it is 1 month or 2 months or 6 months. You know that it is all just moving towards the end and the entire journey is filled with death and bitterness. Then you fight harder, even if it is only until the next corner. (Dr Art. Interview2, audio 10212)

I am aggressive within the framework of my knowledge ... I'm open to new treatments. To be completely honest, I am tempted to prescribe a treatment where it may not be needed; where it may even do harm; the goal being any sort of gain. With the hope of gaining more time, fight cancer more effectively; even just put cancer in the corner even for a short while. (Dr Bonus, interview1; 1076)

Following patients' wish for cure and their difficulty in accepting the disease prognosis, was suggested to be one more reason for doctors to persist with curative treatment, although cure was not any more a realistic outcome. Dr Bonus said that patients did not understand when the disease was advanced and therefore not curable, so they insisted on cure. Thus, he continued with active treatment to fulfil patients' wishes.

As a doctor, I don't abandon the patient. I keep fighting until the end... this is what patients expect from me; doctor, don't let me die...I fight my battle, aware of the futility. (Dr Bonus, audio 10087)

Because in this country patients do not understand that there is a distinction between early and advanced stage of the disease their demands are the same. They want to get well. As a result, regarding my response to them, I try to do as much as possible for them. (Dr Bonus, consultant; audio 1343)

Another doctor offered another reason for persisting with aggressive treatment, although it might have been futile, i.e. surviving hope. Whilst patient Tamara was dying, he insisted in offering different treatments and when I asked for his reason, he explained that by focusing on sustaining life, he kept hope alive.

If life goes on, there is still hope. As long as you're fighting, you can fight the monster that is despair. (Dr Math, audio 10239)

The hope for cure was maintained even if that meant going against the survival statistics. Beating the death statistics, according to Dr Art, would be a heroic act, an achievement and personal fulfilment. To this effect, Dr Art disapproved an engagement with prognosis of death and dying. He thought that it was unfair for the oncologists to consider prognosis when choosing treatment for the patients; he instead supported that the focus on curing should be retained despite the negative statistics. According to him, engaging with prognosis could jeopardize the efforts for winning cancer.

The end is something that the doctor can see ...and he sees it based on statistics, I would say. Yet, it is not fair, it is very unfair. That's why I never make predictions; he will live this long or that long. I think it is distasteful ...Whether it is 1 month or 2 months or 6 months, you shouldn't. IF you start playing this game, then the next thing you know is that it is all just moving towards the end and the entire journey is filled with death. ... I fight for them as though I could disprove the statistics (Dr Art, consultant; interview 2, audio 10212)

My observations supported doctors' interview data in relation to care choices for patients. The dying interval between curative phase and death had been kept very short; only a few weeks to some days before death. Patients were treated with active treatment almost to the end of their life. Approximately a week before death, care was focused on palliation; i.e. stopping chemotherapy, care comforting on symptoms and discussions about imminent death with the family members.

Sila does not respond to any more chemotherapy; instead one more metastasis was diagnosed lately in her spinal cord. She is suffering from the ascites which make her quite breathless. She now needs help to move in bed and often needs to be bed bathed. She is developing jaundice and she is drowsier. I think Sila is moving into her last phase, but she is not told. Today Dr Bonus had a discussion with her about another treatment choice. Nonetheless he called her sister and told her that things were not good but they would not give up on her, they would still try. (Reflective diary, Sept 2006) [Sila died in the hospital a week later.]

Dying phase: 'failure' - doctors disappear from the scene

While 'fighting cancer' and later on 'fighting even more to extend life' were the choices in their mind, doctors seemed to lose their direction when death was imminent. As the main consultants said, the dying phase was manifestation of their failure to defeat cancer. According to them, it was the ultimate proof that they had lost the war against cancer and death; a reminder of their limitations.

Dying is a very uncomfortable time for me; you know that you have lost and that there is nothing else you can do. War is over and you have lost. Death is the winner. (Dr Math, senior registrar, audio 1022)

With failure of cure, doctors distanced themselves from patients, by not visiting them and instead sending more junior doctors to deal with the matter. They removed for a

number of reasons. As they were always focused on cure, they did not see any role they could adopt during this phase.

My role is to fight for cure as an oncologist, not to prepare people for dying (Dr Bonus; consultant; audio 13402)

Most of the doctors believed it was the family's role to deal with the issues around death and dying and not the role of health professionals. Dr Bonus suggested patients could not have a good death if families did not prepare them to die and did not have confidence to provide care at home. In the case of Maria, Dr Art said: *'There was no hope for a good death, because the patient and the family did not prepare well'*.

However, doctors said that they were sad when patients who they bonded with were dying and thus they said they could not become a witness to their dying.

It really hurts when you lose someone you like. Always; The sadness... I go through it before death I cannot see them dying. After it happens, it is just something that happened and it's over. You feel the sadness until it gets to that. (Dr Bonus, audio 10087)

For some doctors, the dying patients were a reminder of human mortality, which they preferred not to face.

Dying is a very difficult thing. Patients' deterioration is one of the hardest things to deal with. I find hard to deal with patients' degradation of their body and their soul, the way their body is ridiculed as it wastes away, they become incontinent, pained, and weak. I rather stick with the brave fighting. (Dr Art, audio10346)

Nonetheless, doctors stated that they lacked training in dealing with dying and therefore thought they were unable to support patients or a good death.

I lack training and I don't know what to say at those times. Even though I may try to support, am not sure if anyone is listening. (Dr Bonus, interview1, audio)

7.3.2 Attitudes towards death and dying: 'death is a horrible thing'

'Death from cancer is horrible and cancer is a beast'

Doctors described death, as a 'horrible', 'bad thing'. They thought that particular the death from cancer was not natural, especially in the case of young people, and thus they said they could not accept it. They used terms which refer to death as a living creature, which needed to be killed (Death [θάνατος] is a male noun, not a neuter in the Greek language). Death was named as 'a monster' or 'an enemy', which needed to be defeated. It was also attributed with powers of 'a superior agent'. Doctors often employing war terms, they argued that they had to fight an uneven battle with death, because most of their patients eventually died, hence death prevailed.

I think that a "good death" is an oxymoron...Death is a bad thing, so it cannot be good; this loss and in such a violent and unreasonable way. It is not natural aging and wearing down. It is a disease that was developed in most cases at a younger age. It is a very ugly thing; possibly one of the ugliest things. (Dr Anton, audio 12341)

The following quote from Dr Art, illustrates the metaphorical language used to express his view of cancer being a 'live monster' that kills people to death:

Death is not a natural thing. Not at least the death which comes with cancer. How can I accept death as normal when I see young people of the age of 20, 30 dying? Cancer is eating people alive. I keep noticing people's beauty when they come to me with early diagnosis and at the end how they die deformed, ugly. (Dr Art, consultant; interview 3, audio 12301)

Doctors associated cancer with death, despite the general attitude of the hospital fighting cancer and saving people's life. Dr Art explained:

My job is to win against cancer, but cancer is bonded with death, so I have to fight with another agent which is death; how can I extricate death from the disease? (Dr Art, consultant; interview 3, audio12300)

Dying: 'waiting for the death sentence'

The advanced cancer phase and dying seemed to be very challenging for doctors. Dying patients was the evidence that doctors had lost the battle for cure. The limitations of medical science seemed to be taken personally; they expressed the view that the dying and death of a patient was a moment of personal failure for them, as they had failed in their goal of curing the patient. Often they used the expression of '*losing a patient*', or '*losing the battle*'.

Dr Anton explained after the death of one participant, that the patients' death was not only emotionally difficult, but a reminder of his limitations. He said he could not see any other way of helping patients, when he could no longer cure them.

This is a difficult time for a doctor. Curing them is the ultimate goal. Cure without doubt... it's unquestionable. But when a patient dies, then he [the doctor] has to admit that his knowledge no longer mean anything. You did what you could do, but still you could not help. (Dr Anton, senior registrar; audio 10219)

Dr Bonus explained his experience of working with patients with advanced cancer, describing this phase as a waiting for '*the death sentence*'. He also said that he felt trapped in this situation unable to stop death. He even expressed concerns about the benefit of the offered treatment during that time. In two occasions, he compared the hospital with a prison, where people had to be and eventually die in.

It [death]'s horrible thing; you experience death over and over again. You are put in a cell with people sentenced to death and every day one is taken away and shot. And here we're putting that to practice. You see intelligent people who just get dyspnoea and at the end they will pass, and you punish them in this Guantanamo. And they are happy to be in this cage. (Dr Bonus, consultant; audio 10111)

According to Dr Art, treating cancer resembled a journey in through a tunnel which either ended in *light* (cure) or *darkness* (death). He, therefore, viewed dying as darkness which brought feelings of despair to the doctors:

This [dying] is truly a very exhausting stage for the doctor. It is a stage that brings horrible bitterness and sometimes despairs. The moment when you see that there is a relapse you know the patient is dying; that moment of relapse where in the end of the tunnel you see darkness and not light... (Dr Art, consultant; interview2, 10232)

Good death or an oxymoron?

Although death was described as a bad thing there were a few occasions when some of the doctors discussed the option of a good death. Since death was unavoidable in many cases the option of patients having their loved ones next to them at that time seemed the most appropriate thing. A family's presence and symptom control- especially pain management- were the two most important things near death according to doctors' views.

[Good death is] quiet, with their loved ones by their side; in their beloved environment, wherever that may be; their house, their villa, their penthouse, their garden; wherever. Not the hospital where we keep them locked up. ... and of course a death without distress, particularly caused by uncontrolled pain. (Dr Bonus, consultant; audio 3422)

The rest of the doctors allied with the view that a good death is the natural death and since cancer death could not be seen as natural, then a good death was an oxymoron. Dr Art expressed the view that a dignified death could be only the sudden death, a death which has not resulted after a slow deterioration; hence death from cancer could not be considered as such.

There can't be any dignified death, or good death, whatever you call it. The only dignified death is when you die unexpectedly. A dignified death without losing control of all these bodily functions cannot exist. It can only be in a sudden interruption; a sudden death; sudden interruption of life. (Dr Art, interview 3, audio 12301)

7.3.3 Doctors' relationship with families

Family as a supporter

Data suggests that doctors viewed families as part of the care team. They considered the relationship with patients' families very important, for two reasons: a) they could share responsibility of treatment choice with the family, by breaking significant news to them instead of the patients; and b) families would play the role of convincing patients about the choices made and encourage their compliance, whilst supporting them at the same time.

It is not easy to talk to patients about the uncertainty of the treatment; family can help with this and help the patient as well. I said to the daughters of a patient I didn't even know: "What we should do according to what we know is this. It is possible - and this is about the matter of information we have so far - it's very much possible that we are wrong. It's possible that she will get this treatment for nothing. ... But if she's not in that category of patients who would get this treatment for nothing, this may save her. All these are not things that you can tell fully to a patient. I believe that you can tell all this to his loved

ones; to those who you have seen that they truly care about him and can know what he wants. (Dr Art, consultant, audio 3209)

They [families] can help my work when they realise the importance of a diagnosis, the importance of prognosis and the importance of supportive care. And when they understand all that, they help in all those areas, as they are the ones influencing patients the most. (Dr Math; audio 4410)

Doctors' relationships with families appeared to be as equals as both of them seemed to share the decision-making over a patient's treatment and care. A closer look though, might suggest that families were often provided with information in a certain way so that they would support doctors' views and convince patients about it, rather than discussing different options and making choices together. Hence, doctors' responsibilities lay in helping family understand the situation at every time point, so that they can effectively guide and support patients.

I believe that a part of my role is to make the relatives understand the gravity of the problem of the patient, what science can do for him, what they can do and what I can offer. When family understands what should be done, then they can help with making patients follow. (Dr.Anton, senior registrar; audio 10166)

I need to explain to families the limitations of medicine when cure is not an option anymore, so that they can help patient accept it. (Dr Bonus; audio: 1072)

Particularly near the end of life, doctors thought that families had the primary role of patient support. Helping patients through the dying process was considered a task for the family and not for the health care team.

I believe that in Greece the family is still the main means of support. ... I believe that in most cases it is a job for patients' loved ones. Families have to deal with patients' awareness of their disease and of their dying. They are the ones who

need to be with patients; ...that's the way that people used to die anyway. Now they die in a random, faceless hospital bed. (Dr Art, consultant; interview 3; audio 12301)

Within the doctor-family relationship, doctors aimed at keeping families satisfied as they considered family gratitude towards them important. Family's gratitude offered doctors job satisfaction and balanced out the sadness of the amount of patient death. It boosted their motivation to continue exercising their profession.

Oncology is really tough; you are faced with patients' death all the time. When families are happy with you and treat you as their saver, it makes you feel nice. You find a meaning in trying, because what you do might not reflect on patient cure but at least somebody is grateful about it. (Dr Math, registrar; audio 10230)

Dr Art exemplified the importance of family's gratitude by describing it as 'the *greatest reward*':

I am satisfied when I see gratitude in patients' eyes; and in their relatives as well. This... it's false of course but it is a kind of worship. This worship is the greatest reward for me and the most lasting reward; it's what makes me keep coming here every day. (Dr Art, consultant; audio 1344)

Family as a barrier/burden

However when families challenged doctors' decision-making and expressed different preferences, the doctors perceived families as becoming a barrier between doctors and patients. During those times, doctors acknowledged the challenge of families' power of controlling the information given to patients, but also of making choices on their behalf. Dr Bonus suggested that by handing over such responsibility to families, they might have occasionally put patients at risk, as sometimes families might make decisions based not on patients' best interest but based on their own agendas; for example personal guilt,

inability to accept of patient dying; family competing interests such as inheritance matters. Nonetheless, doctors did not see a role in supporting families to cope with those situations.

And let me tell you why a family will put up walls, the family is who cannot take care of the problem. So they are in denial. They can't handle the patient, they can't handle a patient who knows about it and they can't handle knowing the problem themselves and this is why they try by hiding it from the patient to repress it from their knowledge. (Dr, Bonus, consultant; audio 126)

Even if there is a case of a patient who wants to know their illness, family is still the barrier between doctor and patient. It's hard for the family to handle the truth of patients' dying; avoiding is a kind of management; but then it is their problem. (Dr. Art, consultant; audio 10172)

My observations with regards to patient Giorgos confirmed the above attitude. During the time that Giorgos' wife did not cope with Giorgos' illness progression and the increased demands of care, Dr Bonus worried that she would create problems in their collaboration. Instead of exploring ways of supporting both patient and family, he rather chose to transfer the care of Giorgos to another colleague.

Another problem in the family- doctor relationship was described to be families' unrealistic expectations. Dr Art said that families became a burden for the doctors when they requested more than the doctors could offer. i.e. insisting for cure when that was not possible. This made him feel weak and unable to offer solutions.

'This is a very complicated matter. I think that the family makes my work harder when they ask for unreasonable things, things that are outside of the patients, beyond what is possible. They ask for things that are beyond my

abilities and this gives me a feeling that is hard to bear it. (Dr Art, consultant; interview 1, audio 1029)

Particularly with place of death, Dr Bonus argued that in several cases, he supported the patient going home and dying there, trying to follow the patient's wish. However, families most often opposed such a suggestion, because they felt they could not cope with the patient at home and in those cases, families' preferences were heard.

In many cases it is the family. "Then there's something else, they say, what will I do with him at home, keep him here." We say he doesn't have to be here, he just needs some oxygen, getting water and painkillers. "And what will I do with him at home?" (Dr Bonus, consultant; interview 2; audio 11881)

However, in the case of Sotos, I recorded Dr Bonus threatening the family that if they were taking the patient home, they would become fully responsible for his death and that the patient would bleed from everywhere. At that time, Dr Bonus explained that this case was different, as the patient would be taken back into the mountains; to his village and that there would be no available care or support for the patient. He also worried that the family might sue him for the death of the patient, as they had not managed to accept Sotiris imminent death.

7.3.4 Doctor-patient relationship: 'patients need to trust and follow medical orders'

Doctors said that a trusting relationship was very important in order to help the patient. But this relationship was often based on emotions and not rational judgements or thoughts. Dr B. explained he had chosen to give false hopes and expectations in order to gain patients' trust. Even though these expectations eventually would not be met, patients would still trust doctors as the relationship was already based on emotions and not rationale.

Doc: We create false hopes, false expectations, when they are not met they want to know why.

Researcher: Do they stop trusting you then?

Doc: No, Greeks are either stupidly trusting from the beginning, I mean with no particular reason or stupidly mistrust ... this is all feeling. Reason doesn't enter into it at all, it's all feeling.

According to Dr Bonus, patients were never mature enough to accept the truth; that was another reason he would offer false hopes. According to his experience, patients did not prepare to know the truth, even if they were told their diagnosis. Dr Bonus suggested that patients were not willing to accept their condition and in a way they forced him to play the game of false hopes.

We wouldn't be telling the truth because no one is mature enough. ...They don't have the maturity to handle it... they themselves sets limits. He says, doctor, I know that I have a malignancy that can be cured. Tell me what we're going to do. ... Or he may be saying "Doctor, I know this is nothing, I got it when I banged my leg". That's as far as they are willing to know. So then what do you do? You play along with this.

However, Dr Bonus recognised that patients near the end could understand their condition, regardless of whether they are told or not. Nevertheless, he had nothing to suggest for this stage. He felt it was the family's role to prepare patients for their death.

End stage patients know what is wrong with them. I believe that all end stage patients are aware of their condition. Some of them say it out loud, others admit it but they don't want to hear it and others both admit it and don't care about hearing it. ... It is the family who knows how to help at this stage, not me.

Doctors, often said that the relationship between the doctor and the patient relied on one thing; cure. Dr Anton, explained that patients had clear expectations of getting well and also anticipated that their doctor was there to save them; this attitude made them very attached to their doctors.

From my experience patients get very attached to their doctors. I believe that the doctor-patient relationship is quite complex. A patient coming to see a doctor doesn't come to hear that everything is going to go badly. ... They go to a doctor to get well. If they went and heard the worst possible predictions, they wouldn't go at all. Patients want only one thing- their health. They don't ask for anything more or anything less.

A few consultants supported that they tried to encourage patients' hope so that patients would retain a good mental state. This way, patients would remain compliant and accept the treatment offered by the doctor. Dr Art's view on the matter follows:

The doctor should encourage patients to stay in the battle by giving them hope. When this is not possible, the doctor should manipulate the patients' mood by pointing to the little positive markers, regardless of their significance to the disease progress; this way, patients will not give up on the treatment choices which the doctor had made for them. (Dr Art, audio1029)

7.4 Nurses

In this study, nurses were not observed to play any important role in decision-making in relation to patients' treatment and care. They rather seem to focus on a task base care. However, they seemed to play an important role in influencing patients' experiences in the everyday life of the hospital.

7.4.1 Care provision

Task-based care

Patient care was organised on a tasks/duties base around the clock. Every shift organised the care, according to the tasks that need to be completed and nurses were allocated to them. That meant that nurses were responsible i.e. for the IV medication, chemotherapy administration, oral medication, measurement of temperature-blood pressure and glucose levels, washing patients and making beds (usually by nurse assistants). According to this organisation, it was possible that most of the nurses would deal with all the patients during the same shift, but only from the perspective of their duty. The notion of patient centred care, where nurses would be responsible for patients rather than duties was not observed.

I went to the ward at 7.30 as I had informed them the previous day. The handover of the night shift was almost finished... The nurse under the sister, allocated nurses to tasks, while confirming with them if that was ok for them. ... I agreed on helping with the making beds, as I had decided to adopt the role of nurse assistant. (Field note, morning shift; 20 days of fieldwork)

I am shadowing Maria. She is delivering the IV medication. ...We entered all the rooms and she administered the medication to the relevant patients. She said that the medication was too much that morning, so she had to be quick in order the patient to receive their medication on time. She hardly spoke to them as she was moving fast from one to the other. (Research diary, morning shift; 4 months of fieldwork)

The time nurses spent next to the patients depended on the relevant task every time. Nurses stayed in the room focusing on the relevant task and left the room immediately after they had completed it. Additionally, data revealed that the more the patient illness progressed, the less they approached the bed (if

possible), and the less they spoke to the patient (Field note, 2 months of fieldwork, afternoon shift).

We entered the room 1504. Sofia offered the first patient on her left the little envelope with his medication. She teased him saying that she brought him his drugs, he laughed. She moved to the second patient and told him that it was his heart medication, so that he would not have to worry. He thanked her. She asked them if they needed anything else, the second patient asked for some water. We then moved to the third patient [advanced stage]. He was observing all along without saying anything. He had an oxygen mask on and seemed to have dyspnoea. She put the bronchodilator in the relevant mask, and put it on the patient. She gave the little envelope with the pills to his carer; she said nothing. We left the room. (Field note, 50 days of fieldwork, afternoon shift)

When the task-based care was delivered, nurses spent less time with advanced cancer patients, but gave more time to their carers. Nurses were observed to spend more time with families whose patient was terminally ill, rather than the others' families. They spent time to explain what families could do more for their patients in terms of helping with their care and let them stay more in the nursing office.

Maria's mother came in the office. Effie asked her to come and sit with us. She brought her some water. She looked at us and tears came to their eyes. Effie held her hand and told her to have courage. She shook her head. ... Maria's mum asked what else she could do to comfort her. Effie gave her a glycerine cream and explained how to take care of Maria's lips, as they were getting dry due to the constant oxygen mask. (Field note, 3 months of fieldwork, afternoon shift)

We left the room. Mrs Kelly's husband followed us. Eleni stopped and asked if she could help him. He thanked her for helping him with washing her [his wife] up. Eleni smiled and touched him on his shoulder. He asked if there was something,

he could do more for his wife. Eleni moved towards the office while speaking to him. He came along. She explained to him how to lift up his wife to help her with dyspnoea and explained how to move her in order to make her feel more comfortable. He left, we then continued the IV round. ...I was surprised as she operated always in rush when she was in rounds and this time she interrupted the round for him, talked to him in the office and then continued with the IV round. (Field notes, 2 months of fieldwork, afternoon shift)

Nurses of the ward Mariza focused more on the delivery of medical treatment, physical care and sometimes on symptom control. As the ward Mariza was one of the main wards for active treatment, the patients' turnover was very high and the load for chemotherapy delivery was one of the highest in the hospital. During the nursing handovers and also nursing notes, nurses mostly reported about chemotherapy treatments, patients' reactions to treatments, blood transfusions, side effects, blood test results, plans of treatments as prescribed by the doctors. Occasionally they reported complaints of patients in relation to pain or dyspnoea. Only in a few occasions, patients' psycho-social needs were reported. In those occasions, the social worker or the psychiatrist were involved and thus reported.

To Mrs Koliou at 10 at night, a catheter to have a bronchoscopy the next day, Monday she's getting a bronchoscopy. Normal/Saline for three hours. Tomorrow morning she will start a 24 hour urine collection. But she has a folley [urine catheter]. We took the blood sample to check the sodium. Mrs Georgiou had a platinum treatment, she is continuing with 5U, at the same time as hydration IV. Mr Zenias. I gave him 6 mg Zideron; blood sugar 135. We were just checking on him in case he got a hypoglycaemic episode. They just gave him this morning 20 instead of 30 insulin units because he had a low. Mr Ntasis is out on leave. Mr Michas got a treatment today and he's continuing with hydration. (extract from nursing handover; audio 10025)

...Kula about to get discharged. She was going home in Kalamata [rural city] today. The ambulance came but refused to take her without a family escort. Social services called to find a solution, no family around. A new referral should be made (translation from nurses' notes; Koula's folder; morning shift; ten days before Kula's death)

Lack of autonomy/responsibility in symptom control

Some nurses who held a bachelor's degree expressed the wish to have responsibility over symptom management. They did not appreciate that they had no involvement in the decision-making of care. They explained that despite the relevant training they had for symptom control, they were not allowed to practice it autonomously, but instead they needed to have the doctors' written approval, even if they did not know best. Such regulation, made them feel powerless and sometimes made them feel stressed, as they had the knowledge to understand that the patients were not managed well. A few nurses stated that in some occasions they had intervened by themselves, as they could not get the doctors response.

The doctors control it [pain management] by themselves. They give Durogesic, increase it, administer morphine... all that. Whether they follow protocols, you can hardly say. Very rarely they consult the pain team and very often get it wrong. I have followed special training in pain management, but I am not allowed to use this knowledge into practice. Sometimes, I wish I did not know much; then I would not feel so stressed and helpless. (Nurse R; audio 10168)

'I am in pain' he said. 'Help me'. 'Why don't you ask for the doctors?' I said. 'They are not doing anything for me'. 'Don't worry' I said to him, 'I'll find them'. I came back in the office, checked his notes, no instructions for pain. I gave him Lonargal and right after I gave him Dynastat. It wasn't written anywhere; I left morphine for the end. I didn't say that I did all that by myself; I said that a doctor

had ordered it. What doctor? Why don't they pass this to us? (Nurse Poppy; audio 10111)

On several occasions, I witnessed nurses trying to guide family members on how to negotiate better care for their patient member. They offered insights of the unwritten rules which clinics operated and helped them manipulate the system in order to receive faster or extra services.

... I talked to the mother... That was the only good thing about yesterday. I said to the mother I'm sorry but because we had that situation yesterday, why don't you ask from the doctor to have our psychologist see him, I'm not saying that you need a psychiatrist, that's for different cases but he too can help. Our psychologist is very good and he'll discuss things with him because there are some things I can't help with. (Nurse Pat; audio10170)

Petra [nurse] took Jella aside and with low voice suggested her to go to find the orthopaedics herself and get them to see Pablo. She said that the oncologists would take time to sort this out, due to workload and not the best relationship with the orthopaedics. She would make things happens faster if she was approaching them herself. (Field notes, Pablo data; 5 months before death)

7.4.2 No power and space to develop truthful relationships with patients

Nurses expressed a sense of being powerless in their relationship with patients. They often expressed discomfort when patients challenged their prognosis or even diagnosis and requested test results from the nurses. Nurses felt that they were trapped between the families and doctors decisions and that they had no choice but to comply with this. Such situations resulted from their wish of withdrawing from communicating with patients, as they felt they cheated on them. As Effie said, they did not feel they had the space to develop communication with patients, and therefore explore wishes, preferences and needs, as anyway they would not be involved in the relevant decisions.

Effie: Yes, when this happens I feel useless. Sometimes, they ask about test results or other things to get their info indirectly and you can understand it. But I don't like it when they have lied to the patient and I have to comply with this, as I cannot say anything – nurses are not allowed to. I become so mad at them and there are times I don't want to communicate with patients, especially if they have not been informed the truth about their situation. (Dialogue2 from Field notes 21 Feb 2006, afternoon shift)

What kind of a relationship can you have with a patient who is suspecting that we are hiding information and you go along with this? Pedro asked me today about the CT scan results and said I was not aware off. I could see he did not believe me. It is so embarrassing; I rather avoid him now (Roula, 4 May 2007, morning shift)

However, some nurses found it relieving that they did not have authority over informing patients and discussing care plans, as this would request more time investment on their behalf and would result in an extra emotional burden. Besides, they said that they did not have training in dealing with bad news and death and dying.

7.4.3 Nurses' attitudes towards death and dying

Cancer death is not a good death

Nurses discussed ideas of good death only when I tried to initiate such a discussion. Observational data, though, showed that nurses occasionally expressed wishes of 'a good death' for some dying patients. Nevertheless, I never observed nurses trying to discover patients or relatives' preferences. Their efforts were based on their own ideas about good death. They argued that a good death was a sudden death, not suffering, with the loved ones next and die before develop any dependencies - 'On your feet'.

Researcher: So, what is a good death? Why is Mrs Lena not dying well?

Nurse Effie: To me, good death is not suffering, not pain

Nurse Con: Good death, mmm..., to me is dying on my feet. Dying stuck in bed, hoping somebody to help you is not a good one.

Nurse Eleni: To me it is the sudden death. Before you realise it, you have gone; No loss, no nothing.

Nurse Maria: I agree, but to me a good death is not to die alone. Like Vaggelis, when he died, his whole family was there. You missed this one Despina. He left before you come

Nurse Eleni: I agree, imagine dying and nobody finds out for some days (Informal conversation, 2 March 2006, morning shift, audio 1083)

However, one nurse who had 10 years of experience and communicated closely with patients and families expressed a different thought about death.

...maybe they are dealing with it like it's a natural thing exactly because it's happening little by little. They have the time to realise it. I don't know. ... Or rather, you know what? It looks worse to us than it is because we are scared at the idea of death and we can't deal with it and see how they see it. We are more afraid than them. And we can't grasp how it is... besides they are so tired in the end, they might give in. but they are the ones who actually experiencing it, so we do not really know (Nurse Effie, night shift after Petros' death; audio 10231)

Nurses said that patients who died from cancer usually had horrible deaths with uncontrolled symptoms, and completely relying on others' kindness for help. Some said that they would never wish a cancer death for the people they cared.

We enter the room 1501. Eleni points to the first patient at our left and says to me. 'She will have gone very soon'. She walks towards the patient who is in a

lateral right position with her eyes closed; looks like she sleeps. Eleni checks the blood pressure. ... We leave the room, Eleni says she will call her sister because she might die tonight and it is not nice if she dies alone. (Field note, 19 March 2006, afternoon shift)

I think dying from cancer is one of the worse deaths. You die slowly- slowly, day by day. This is a torture. And then you might have uncontrolled pain or dyspnoea. You see patients here fearing to die as other patients died next to them. Terrible; I wish I could stay out of it (Eleni, 04030)

The notion of a cancer death not being a good death, often initiated nurses from distancing themselves from terminally ill patients. They felt that there was nothing they could do for them, as anyway they were dying a not good death and nothing could change this. Also, often they related patients' death with the fear of having a similar death in the future; either themselves or other family members.

... am staying far from Maria. I know she is dying but there is nothing I can do. She is dying and she is dying alone. She is in pain and there is nothing to do about it. Just makes me so frustrated to witness it, so I am not going there. It makes you fear if one day it is you; you never know (Con, audio 02342).

I cannot tolerate Giorgos. He is dying because of his smoking. Look at him now. I keep telling my father that he might get cancer and die like this. I keep telling him how terrible death it can be and he does not listen. I just go in the room quickly, do my job and leave, before he gets the chance to say something (Marianna; audio 343).

The taboo of using the word death

Most of the times, nurses reported on a death or talked about somebody who died using other words, rather than death or died. They gave several explanations about it, when I

confirm with them that they actually do so. They said that either it was black humour, or that they developed a code so that they could understand each other without shocking relatives or other patients. They also argued that it was probably their way of coping with it or perhaps avoiding it.

When your patients die with such frequency, you cannot name death all the time, otherwise, you will end up talking about death constantly. And that will put you down. I guess, humour is a way of coping. (Eleni's interview, audio 1021)

Examples of these words included:

During hand over, Lina said that Mrs Kula left us yesterday afternoon. (Field notes, shadowing nurses; morning handover)

When Sila died, Lena reported back in the office that Sila slept. Nurses understood the code and called for the doctors (Field notes; after Sila's death)

'They parcelled him. He is new in the box'. [Literal translation from Greek] I had never heard of such expressions before, so I asked them to explain what they meant. They laughed and said that this way nobody else could understand and thus not getting shocked. (Research diary, morning shift; first month of fieldwork)

Understanding dying process

Nurses of the ward Rallou in particular, said they understood dying and in some cases helped the families to cope with it. Since in the ward Rallou, mostly dying patients were admitted, nurses had witnessed dying and death very frequently. They offered experiences of dying processes and described patients' stories during those last moments. They also said that they could understand the signals given by the patients, and when possible tried to help them achieve their way out. This experience had made re-evaluate their life.

I had a lad in 1506, it was the Friday before Easter and he was saying to me "Please nurse, I want to see a priest". Ok, I said, I sent a paper [referral] to the priest, I informed the person in charge because he was in the service. The priest didn't come. And I would get inside the room and he would say "Will he come?" He was looking at me, he was expecting something. He wanted the priest to come. I knew then that death was near. I said "He'll come." I was trying to calm him. He died an hour later. (Nurse Eleni, audio 10267)

He [a patient] said that everything was bathed in light and he had loved ones there; why should I be afraid when I hear such words? (Nurse Maria, 10259)

...I have changed my entire life philosophy since coming here; a year ago. And others don't understand me, because people are afraid to talk about life and death; hardship and sickness; while we are dealing with death every day. I personally consider it...(Nurse Effie, audio 10244)

Because as sacred as it is to show all your love and your care to a person who comes here and gets well and goes home, it is equally sacred to help them, with all your love to leave when they die. There should be dignity in death, because that's where life begins. They need to get a good sendoff here and a good welcoming when they go up. ... A proper sendoff is to be serene when they die and to have their soul be unburdened. Love chases fear away; this is what they need, so they will not be bitter when they go. Love makes people's soul lighter. This is what I say to the families who stay next to patients and they accept it; they say that it is comforting, that this is something they can really give to the patient. (Des, discussion after Tamara's death; audio 102101)

7.4.4 Nurses expectations of families

The relationship between nurses and families was not clear. There were contradictions in the expectations from both sides, which caused tension in the relationship between

nurses and families sometimes. However, it seems that there was a connection of need between them. They tried to have a good relationship because they needed each other.

We need them and they need us. ... Their role is to be with their patient and help him/ her' ... I must say that there are times I love them and then I hate them. Sometimes I would wish I could do without them and yet I am obliged to have them on my head because I need them. You know, there are times you lose your patience. They think they have become experts and they know everything and they tell you how to do your job. They criticise what you do, as if they know. They think they know best for what their patient need, and we know that they just force their patients to do what they want or need. But then again, you cannot send them away because you need them (Field note, afternoon shift; 6 months of fieldwork).

Nurses understood that it was the family's role to perform the 'simple tasks' and if they did not act as such, nurses complained. Families helped with washing the patients; they change the bedding if it was not very complicated, such as patient being connected to machines or having more than two catheters, etc. Moreover, they were present when nurses intervene with patients and they pay attention to drips. However, nurses saw a role in training the families to look after their patient member. In one occasion, when a new patient was submitted, a nurse complained that she could not train anymore families that day, and surely somebody else could welcome the patient instead of her. There were several occasions where nurses explained to families how to assess some symptoms, and taught them how to wash patients, how to move them, how to change beddings, etc.

The cardiologist asked for Fritos fluids balance (intake-outtake) to be recorded. Nurse Paola printed out an A4 sheet of paper which had a table for the fluid balance. The timetable was based on the nursing shift rota, so that at the end of

each shift, they would copy Fritos' records to the nursing file. And each shift per day was divided into intake and waste fluids. She asked Fritos' wife to be responsible for this and she explained to her how to keep the records of the fluids. She gave her a bottle with ml measurements on, for Fritos to measure his urine. His wife said she could not keep it all the time, as she could not be next to Fritos 24/7. The nurse then said she hoped she did not imply that nurses should do it for him. She told her that they had too many patients and that she should learn to do it. (Research diary; morning shift; Fritos case; 32 days before death)

On the other hand, there are times that nurses considered families as intrusive or interfering to their work. Especially when patients became terminally ill, families seem to seek more control on activities and decisions and nurses perceived it as overstepping their role (research diary 18 March 2006, morning shift). Nevertheless, it was observed that when they provided care to terminally ill patients, they talked to relatives, explaining what they did, as if patients were not present.

Effie washed Maria because she had blood all over after the efforts of a central line. Her mother assisted Effie. She kept correcting Effie, something like: 'don't hold her from here when you move her', or 'watch out the catheter- you are not careful', or 'you should give her a blood transfusion today, she is very weak'. I think Effie was upset. She was looking at me every time the mother was making a suggestion. ...When we left the room Effie said 'at the end they tell you how to do your job, they think they know best what the patient needs. When their patient is dying they become unbearable. (Research diary, morning shift; 3 months of fieldwork)

Nurses seem to appreciate a level of intimacy with families, not only out of need. I observed occasions where nurses hugged relatives, or touched them on the shoulder while talking to them. Relatives behaved similarly. The more patients stay in, the more

nurses connected with families. As mentioned before, they tried to comfort families when their patient died, especially those they had bonded with. Nurses valued the care families provided to their patients and there were times they treated them as members of the team. Some nurses argued that they felt like they were becoming members of the families of patients, particularly if patients stayed for a long time in the ward. I observed incidences, where a nurse called a relative grandpa and another nurse called someone mummy. However, these occasions have been observed mostly in the afternoon or early night shifts, and less in the morning ones; perhaps because it is more crowded and busy in the mornings.

We are like a family; you don't really need to send them away. They are very familiar with the processes and they also help if needed' (Field note, afternoon shift; 2 months of fieldwork)

During the oral medication round, I heard a few people asking Eleni how her sick kid was and if she had decided to change it school. She answered and it looked like they had discussed it before. (Research diary, afternoon shift; 4 months of fieldwork)

The relative of the patient with the lymphoma brought Sofia the recipe for a pudding Sofia had requested before. (Field note, 19 Jan, morning shift)

In several occasions, it seemed that relatives felt comfortable to enter the nursing office and sit with nurses to talk, probably asking for support. Nurses gave them a seat and let them offload, offering a glass of water or coffee.

She started with an issue of her patient but after a few minutes, she started crying. She said she was so tired, she could not keep up and that she feared he would die; that they have lost the game with cancer. Nurses asked her to sit with them near the table, offered her hot coffee, and tried to support her. They told

her to have courage while they were holding her hands or stroking her at her back. (Research diary 4 Feb 2006, afternoon shift)

Nonetheless, nurses suggested that it was not their role to support families. One nurse suggested that nurses could not afford to. Their supportive behaviour was explained as more of an act of humanistic attitude rather than that of a professional intervention. It seemed also that family members had their preferences about whom they would turn to. It was been observed that some nurses particularly are approached more by families for help and support. When I asked these nurses why this is happening, they argued that families tend to refer to those who are more available or willing.

Maria explained to me when we returned to the office that this man was devastated by his wife imminent death and that he spends mornings and nights next to his wife being afraid that she would die in his absence. When I asked her why she tried to support him, she replied that she did not provide any support; she just had a sympathetic attitude to the man's drama. I think I should discuss with her what she thinks her role is and try to explore why she did not consider herself supportive. (Research diary, 19 March, afternoon shift)

7.4.5 Relationship with patients

Nurses seem to bond with those patients and relatives with whom they identify areas of attachment. Such areas have been claimed to be the same age, similar roles or similar character. It also seems that attitudes of preference in care are related to the emotional attachment.

Con: I will go to him; this one is mine. ... He is my age and I like him a lot. I think I can understand him better than the others (Informal conversation, morning shift; 5 months of fieldwork).

Eleni: I do understand this patient who fights to live. She has kids and she needs to raise them up. ... If I had the same problem, I would react the same way. I understand her anxiety. ... I will go to her' (Informal conversation, morning shift; 9 months of fieldwork).

Nurses disclosed expectations they had from the patients. They said that they expected the patients to understand their work load and not to be pushy with their requests. They also appreciated those patients who had polite manners. In the opposite occasion, they felt that patients needed boundaries and that nurses should put the limits; if not, patients might take advantage of nurses.

Patients always believe that they are the only person in the world and the only people who is in need at that moment. So we need to put limits. They can go far with their demands and the limit is set at the point where you are giving things to them but they don't appreciate it and they are asking for even more. ...You can judge it from your experience. You know whether someone needs things more. It's your own experience that helps you see this. You can always tell what a patient needs. (Nurse Jane, audio 10090)

She [a patient with bone metastases complaining about pain] I believe, she is just very difficult and keeps demanding more and more. I have seen patients from the beginning when they are standing until their final moments in the hospital when they are dying. I have seen that those patients who were treating you right from the beginning they were treating you right until the end. She has just been difficult from the beginning and now she's becoming even more difficult. (Nurse Nikka, audio 10193).

They will be asking things from Maria [nurse] all the time. Exactly because Maria is more lenient than me, they take advantage of care. Because she will be the one who will give them more than they ought to have. You do the same when

you spend so much time in the rooms; they keep asking you things now. (Nurse Nikka, audio 10198)

7.4.6 The burden of ‘most of your patients being dead’

Nurses - particularly from the ward Rallou (a ward where many patients were admitted to die) - said that the frequency of death often made them feel depressed. They repeatedly suggested that their main concern was that most of their patients died. Death seemed to be connected with a sense of weakness to help patients. Helping the patient was described to be helping him recover or become better. Feeling hopeless to improve patients' state was been reported as part of their burden. Willing to move to another ward, ‘less heavy’ has been often expressed, especially of those working in this ward for more than 7 years.

I want to move; this ward is so heavy, almost all patients will die. I try not to think about it, otherwise I will become crazy. (Field note, morning shift; 16 months of fieldwork)

Don't ask me about patients who will die. I prefer to think that they will live and treat them as they are going to recover. How else I will manage to keep coming to this ward. ... If I knew what is to work in a ward with patients who die, I would never agree to come here, but you need to survive. (Eleni; audio 10138)

The need of resisting of bonding with patients and families has been stated as a way of coping by the nurses who have been working for many years in the field. According to them, this was achieved by not staying in the rooms for long and avoiding any discussions with patients and families. If they did not do so, then they argue that it could take over their life. In this case, the distress was constantly there, even when at home or with their families; they kept thinking of their patients and feel depressed. I also observed that while patients deteriorated, nurses approached them less, unless an intervention required differently.

He [a relative] might need [support], but we cannot afford to for the patients; are we going to take care of relatives too? Who is going to support us? We cannot afford to support everyone here. (Informal conversation; afternoon shift; 3 months of field work)

Eleni explained to me that she does not talk a lot with patients or families so that she will not bond with them and then get hurt when they die. She suggested me to do the same; otherwise, I will not be able to continue with the project for long. She said that she simply does not want to hear what they say. ... When we entered the room 1504 she asked Sofia to keep moving and not get lazy by spending time with patients. She then explained that she had behaved so because Sofia was very young and did not protect herself; she bonded with patients. She had done the same mistake when she had started working there with the result not to have personal life. (Research diary, morning shift; 9 months of fieldwork)

Marianna walked in the room. She approached patients on the left side and gave them their pills. They thanked her. Then she moved towards the right side of the room to Mrs Koula [terminally ill]. She did not go next to bed, but from a distance, she raised the little envelope and nodded to the relative. He came closer, took the pills and then we moved out of the room without saying anything. (Field notes, observation of the nurses, afternoon shift; 6 months in fieldwork)

7.5 Summary

This chapter aimed to provide an understanding of the culture of care of the oncology hospital and its' clinics while exploring the decision-making for patients' treatment and care. In truth it also looked in particular at doctors and nurses and how their attitudes developed over time. Doctors' difficulty of coping with death and attitude towards fighting death and cancer until the end seemed to play the most dominant role in their

process of decision-making for patients' treatment and care. A framework of four dimensions was offered to explore the dominant attitude of fighting for cure; doctors' personal attitudes towards death and dying; their relationship with patients; their relationship with the families and their role in the battle. Doctors' belief that choices for treatment and care were exclusively their responsibility supported a structure that lacked a multi-professional, teamwork approach. The family's position between patient and doctor helped doctors in their choices. The key findings of this chapter are summarised in the box below (Box 7-1).

Box 7-1: Key Findings of chapter 7. Results II

Health care culture

- Care was focused on cancer treatment; no holistic care: focused on cure and prolonging life until the late stages of disease; no space for transition to palliative phase.
- lack of co-ordination of services and lack of psycho-social support
- Relationships giving emphasis on the system; power balance and hierarchy determined by the doctors- no teamwork

Doctors' attitudes and role

- Decision making was doctor centred at the treatment level
- Doctors persisted in fighting against cancer and death. When patient did not respond to treatment, they intensified their efforts.
- Non acceptance of death; no concept of good death
- Doctors perceived families as a supporter in convincing patients but also a burden

Nurses' attitudes and role

- Good death is the sudden death without suffering; not a cancer death
- Nurses focused on task-based care.
- Nurses avoided connecting with patients, due to the burden of dying often with uncontrolled symptoms. Instead they adopted a role in supporting families to deal with dying phase.
- Nurses perceived families as part of the team but also as a barrier.

8. Results III: Family's involvement in patient care

8.1 Introduction

This chapter focuses on the family's role in the patient care. Any family members who were involved in the care of the patients, as observed or documented in interviews, have been considered as the 'patient's family'. In some cases, this was one member of the patient's family (e.g. spouse), in others it was more than one person (e.g. both parents for younger patients, several children for older patients). In a couple of cases, there were times when the broader family (e.g. families of siblings) seemed to have a role. In two cases where the patient had no family or the family lived in a different town, a friend acted as the main informal carer/family member at certain points.

The chapter is organised in two parts. First, families' perceptions of their roles are explored along with the activities they have undertaken. As families believed that their main role was to take responsibility for the patient, and hence to make decisions on their behalf, the next section explores further how the family system operates in terms of decision-making and care provision. Four patterns were identified and the factors influencing decisions are explored. Two family cases are reported in more detail, as they illustrate the different patterns of functioning and decision-making, throughout the patient's trajectory.

8.2 Family's role

The family presented itself as a stable foundation in the unpredictable world of illness and health service environment. Keeping their ill member loved and protected seemed to be their main goal. Families felt they succeeded with this goal, as they were closely involved in providing care but also in making the therapeutic and informative decisions as the patients kept deteriorating. Families tried their best to be always present. They sought to alleviate patients' suffering; to protect them against the pain provoked by the disease; and

perhaps also against the pain caused by the knowledge of their fate. As some family members claimed, telling the truth to the patients and asking them to make decisions about their care was perceived to be a useless form of cruelty, a source of suffering that added to that already inflicted by the disease. Therefore, it was considered normal to keep patients unaware of their prognosis and sometimes even of their diagnosis. In this way, families were more likely to collude and collaborate with the approach of the oncologists.

8.2.1 Be present: cover the patient 24 hours a day

Families considered their duty was to remain next to the patient. I noticed that all families tried to be with the patient 24 hours a day; they constructed and followed their own rota. The whole family adjusted their everyday life around the ill family member while juggling other duties such as employment and looking after other members. In some cases, one member of the family - often the main carer - took unpaid leave or was released from other competing roles in order to devote time to the patient.

During the day, I am always next to him; his mother covers for the night when he sleeps and thus he does not need much. Then I go home to rest so I can manage for the next day. (Giorgos' spouse, audio 10056)

Well, one of us [siblings] needed to be here most of the time, as neither dad nor mum could cope with the hospital. At the beginning we all took some annual leave, but dad has been in hospital for more than three months now. First, Sophie got some sick leave and now I managed to secure some unpaid leave. So we will manage for the time being (Eleni, Sotos' daughter, audio 1240)

Families did not challenge their role of being with the patient at all times; they perceived it as normal practice. There was a notion of the family staying physically together; the hospital seemed to become the extension of home, to which families had moved to support their vulnerable member.

What do you mean [by asking] why we are always here? He is our son and he needs us. Who is going to look after him? We are here to look after him, support him, and help him. We are all one hand and we will all go through this together; so we are staying together. How else? (Con's mother, audio 1200)

Sotos has been in here now for two months. How could we leave him alone? If he needs to be here, we will be here with him; if this is where he needs to be, then this is where his family will live too. (Sotos' wife, audio 101106)

I observed that often families had brought belongings from home - such as chairs (more comfortable than the hospital's), plates, mugs, food - especially when patients had been staying for more than a week in the hospital. Nurses complained that the rooms could not be kept clean and tidy, due to all those things which families accumulated next to the patients.

The bedside tables were packed with many different things. Plates or glasses, fruits, juices, food boxes but also material for the patient care, such as cotton, gloves, gauzes. Roula [nurse] seemed to be mostly annoyed with the plastic chairs which families had brought or rented. She kept saying that there was no space for the staff to do their work and that the rooms could not be cleaned and instead they had been turned into camps. (Field notes, 13 months of fieldwork)

Families' presence next to the patients 24 hours a day, not only serve a supportive purpose, but it also covered practical issues, such as the safety of patients. This was evident particularly with frail patients or patients with mobility difficulties. When the family was unable to be with the patient, especially during the night, they hired a private health assistant, even if only to keep company to the patient and help when needed. If a family could not afford to hire a health assistant, they found this from the broader family's resources. During a few times where patients had been left alone, accidents had occurred. Fritos is an example of this.

Fritos, a patient at his 70s with liver cancer and severe ascites, was quite frail during the last month of his life. His wife, Lola, had health problems and thus she could not stay all nights next to him. They had two married sons who could not help at the time. They also could not afford to pay for a private health assistant; hence some nights Fritos had been left alone while the carers of other patients had offered to keep an eye on him. However, one night he fell while he was returning from the toilet and was discovered by a fellow patient more than 40 minutes later. His wife said she felt guilty and helpless when she was told.

Lola: Did I tell you? Fritos fell last night. Zeta [the carer of the next bed patient] told me this morning. He managed to go to the loo by himself; but then his legs could not hold him and he fell next to his bed with his back on the floor. And he could not get help;

Researcher: What about the nurses?

Lola: It was 23.00; as you know, there are one or two nurses during night but they would not know, unless someone was calling for them. The others [rest of patients and carers in the room] were asleep. Thank God Mr Kostas saw him at one point and went to help him. I cannot stay over nights to look after him, you know my problem with my back; I need to be able to lie down for some hours during the day. Oh God what am I going to do? I should not have left him alone; my poor Fritos. (Lola, Fritos' wife, audio 10241)

Patients seemed to concur with the view of families' duty of presence. They expected their families to be next to them, even if they expressed concerns of overburdening their families. In fact, in a couple of occasions where two patients had been left alone for some hours, they complained.

[Patient on the phone] Where are you Soula? Why did you leave me alone since morning? Who is going to look after me now? I am not letting Despina go before you come. (Fritos, audio 10332)

...I am worried that I have made Jella [his spouse] completely exhausted; but what can I do? This is the time that families stick together. I do hope we go home soon, so she can have some rest; I cannot do without her. (Pablo, audio 10153)

Doctors and nurses also suggested that families should be there, not only because they participated in the provision of care, but also because they were the point of contact on behalf of the patients. If patients did not have their family next to them, often the health professionals would criticise the family for not caring enough of their ill member.

Nurse A: Do you see X? He is left alone for most of the day. I think his family got bored of him. Maybe they had problems in the past, but he will die, they should not let him alone.

Nurse B: Dr Tsoukos was looking for them. They need to discuss the outcome of the CT; what they should from now on. He was quite upset. He said if they do not care why should I? (Nursing hand-over, ward Mariza, audio 10135)

Families were so protective of the patient that health professionals often had to negotiate with the families to step out of the bedside, when required. The nurses had to negotiate with families to leave the room in order to perform interventions and had to explain the families why this was necessary. Doctors, though, did not always allow room for negotiation and refused to engage with relevant complains. Sometimes they declined to enter the room, unless all family members had moved out.

Today Mary (nurse) went to the room 103 with a trolley to check the infected pressure sore of X patient. A surgeon had been called to clean the wound and suggest the care. The patient's wife suggested she would stay next to the patient

in order to see what they would do. She had been looking after her husband's wound, so she wanted to attend. The nurse said she could not stay, but she would be updated later with perhaps the new plan of care. The wife refused to leave and said she would rather help. Mary seemed to be getting frustrated, until the surgeon came and demanded everyone to leave the room. The wife tried to speak to the surgeon, but he refused to listen to her and demanded her to leave the room, otherwise he would not stay to do the job; he said he was too busy to have to negotiate with her. (Field notes; ward Mariza; 18 January 2006)

Only the family and those considered part of the family, could share time in the rota next to the patient. Friends and others visited for some time and then left. The very trusted ones - those who belonged to the circle of family - could stay alone next to patients and provide intimate care if necessary. Similarly, when I felt trusted, I was allowed to become part of the *being-present rota*, and discuss/interview patients alone. Until that point, I could only visit for some time under the gaze of the family.

Today I have been suggested to cover Pablo's for two hours. Pablo's wife had to go and authorise some medication prescription for him. His wife said that now I was one of them, so she would trust me to be next to him. Pablo said he would be very happy to stay with me and confirmed that I had become family to them. I have now been following them for nearly three months. (Field notes for Pablo, 5 months before death)

Today Natasha's father left us alone. ...He told me when he returned from his coffee break that he could now trust that I would not reveal anything which was hidden to her, but also that my research would not harm his daughter. (Field notes for Natasha, 3 months before death)

8.2.2 Family as part of the health care team

Colluding with doctors' decisions

While families felt they had to be next to the patients to help and protect them, at the same time they identify themselves as advocates of the health professionals, especially during the time period they focused on fighting for patient's life. Both families and doctors shared similar goals: to save the patient or keep him/her longer and to defeat cancer, respectively.

The families had been informed about patients' condition by the doctors from the outset, very explicitly and with complete sincerity. The doctors usually suggested the preferred therapeutic path and, when required, the family participated in the decision-making. Most of the families were keeping copies of all the tests and documents of patients' files. Usually they brought them to the appointments with the doctors in order to assist them with assessing illness progress and make decisions.

I asked Jella why she had to bring her copies every time she had a meeting with Pablo's doctors; all copies should be on his file. Jella explained that often tests were going missing and that this way she could always inform doctors about new or missing tests. She said that doctors had appreciated that she was keeping records and thus they relied on her. She explained how she had helped with assessment when bringing copies of previous CT scans for comparison. Also, the doctors always asked her about Pablo's symptoms and she could always tell them if the painkillers had worked. (Field notes, 4 months before death)

Families formed part of the health care team; by being delegated the role of making patients comply with the various or changing care plans. In several occasions they had to recite 'well intentioned lies'. Particularly when patients had started getting tired or questioning more treatment, the families had been 'employed' by the health care team to convince patients, while often promising unrealistic results.

Family carer: My dear, the doctors said that we should do some more therapy... a new course of chemotherapy.

Natasha: NO, mum. Can't you see I cannot take it anymore? I am so tired and all the radiotherapy I did before has not helped much. Has it? Why do they want me to do so?

Family carer: They said it is a new type of therapy and that it will work. They said it would make you ok. So you need to be strong and go for it. Your dad and I will be next to you for this. Ok? Don't say no. (Natasha and her mother, audio1022, 10 days before death)

Families found themselves occasionally standing between the health professionals and the patients, during the course of the patient's illness. At the beginning they seemed to be very close to the doctors' view, especially in relation to information disclosure. Most of the times, they had agreed with the doctor's decision not to inform the patient about the prognosis. Sometimes a relative took the initiative and requested the doctor to disclose nothing; in other cases it was the doctor who more or less implicitly suggested this option.

Of course you cannot tell them this and we agree here with the families. You can't do that when they are taking treatment and they are surviving; it would be particularly cruel to tell them "You know what, you're alive but not for long. The average life-expectancy is six months with your disease". (Dr Bonus, audio 1020)

Challenging doctors' control

However, the more the illness progressed and the more the patients got worse, some families said they thought it was pointless to keep patients unaware of at least the seriousness of their condition or to continue with heavy treatment. They rather seemed to change gradually their focus to the patient's quality of life and wishes. When the doctors' focus did not follow this change, tension developed between them, as the families gained

distance from the health care team's decisions and plans. That was particularly evident when deciding the place of care during the last days of patient's life and place of death.

Dad wants to go back in our home, up in the mountains. The whole family will spend the last moments together with no hospital stuff to interfere...There, dad will be Sotos, not just a bed number which requires blood transfusions and temperature measure every three hours. (Sotos' daughter, audio)

If you decide to take care of him at home, you then have to sign that you take full responsibility for his death. But I must warn you that you will not be able to manage him. He might start bleeding from the ears, eyes and mouth'. (Sotos' doctor, audio 13460, discussion between family and doctor three days before Sotos' death)

Nevertheless, in two cases (Sila and Ursula), the health professionals felt they were forced to comply with families' wishes near the end. The doctors wanted to withdraw treatment and send these patients home, but the main carers opposed it. In both cases, a member of the broader family had stepped in during the last days of patients' life and made those decisions. Sila's niece stepped in and took over decision-making, which meant that the care provided was forced to alter from the original plans. However, she explained to me after Sila died that her efforts aimed at the patient's relief and not at cure. Ursula's carer on the other hand, explained that she was not ready to let Ursula die as they had some past issues to resolve.

I was screaming because they had abandoned her to die with all this suffering; especially the breathlessness. You cannot say there is nothing else to be done. They should find a way to help her. Besides, I was so in despair as I had not seen my aunt during the last month and I was shocked with the changes of her image (Sila's niece, audio 10193)

I think of Ursula's life and I do not understand why she has to die now; she is still so young. She had a tough life by choosing Kostas [her partner] and now life treats her like this. The doctors send her home to die; it is not fair (Maria, Ursula's friend in phone call, audio10104)

Both nurses and doctors stated that having the families as their collaborators had occasionally trapped them into the families' agendas. According to their experience, they believed that families resisted either because they served their own interests or because they had still problems to resolve with the patients.

Well, we rely so much on families that we often trap ourselves in this collaboration. Take the case of X patient. The patient will die and he is ready to discuss the stop of treatment. But the family is not ready; they still have lots to solve among themselves. You saw what happened when I told them that I will speak to the patient anyway. They threaten that they would take the patient away and they would look for another doctor. This is the last X needs. So, now I will follow what the family wants. (Dr Bonus interview, 23May, audio10209)

8.2.3 Making choices for patients' best interest

Families often stated that they are in the best position to understand patients' needs and thus it is their responsibility to make the best choices for the patients. They argued that families should receive all the information regarding the patients, and decided what is best for them. They felt that the patients need to be protected from negative news, and rather focus on fighting for their health. They also stated that patients, being vulnerable due to illness, cannot always think what is best for them. Hence, what happened was that patients were not present in the discussion meetings with the doctors with regards to progress updates, treatment choices and illness prognosis.

Doctors say everything to me and nothing to him. ...and I say to him: "do not worry, doctors informed me and they said that in two years time all will have gone; just be patient". (Giorgos' wife, audio)

You cannot expect him to make a decision now. It is not right; we should [make the decisions]. We cannot burden him with all this. He just needs to know that we will do our best for him and that everything will be fine. (Sotos' son, audio 10233)

At times, when families believed that health professionals had the expertise to help them, they followed their decisions or suggestions without questioning. Such decisions expanded from treatment choices, to suggestions of dietary and personal care. However, occasionally this attitude led to tension between patients and families, especially when patients felt that their preferences had been overlooked.

Don't move your hand. Nurses said if this vein breaks, then they cannot find another one for your drip. I promised I would look after it and make sure you are not naughty. Put the hand there ... Don't get upset; I only say so for your own good. (Iris, Giorgos' wife, audio 110103, 6 months before death)

Why do I need to fight with you to eat? Do you think I am against you? Your doctors said you need to eat proteins to help with healing the bone. So you need to eat, like it or not. ... I am not leaving until you have eaten at least half of it. (Jella, Pablo's wife, audio 12039)

Even though the families controlled the level of patients' involvement, in three cases the patient maintained a certain control of information receiving and decision-making; perhaps due to the fact that the patient had been the dominant member of the family before illness. For instance, Sila (a patient at the age of 67 with relapsed breast cancer and liver, lung and bone metastases) was the dominant member in her family. Despite her

sister being the main carer, Sila had developed and maintained direct communication with her doctor; she was the only case where patient and doctor made decisions together.

I really like Dr Bonus. We speak very directly and I like it. He explained to be that my cancer is back and how we should fight it. He takes time to explain me why I have the symptoms I have and how long it will take. He likes me too; he says I make his life easier. (Sila, audio 1532)

Nonetheless, when the bone and lung metastases were diagnosed, the doctors chose to inform Sila's sister rather than Sila herself. Her doctor explained that when it was just the breast cancer he could still tell her that they could fight it, but when the metastases were identified, he realised that there was nothing he could do, and that he could not share this with Sila, whom he had bonded with. From that point and after, he maintained communication with regards to symptoms and interventions, but never told her the truth about her prognosis. When Sila became quite fatigued, her eldest niece took over the decisions about care. Sila's niece had a completely different opinion from her doctor, as she wanted to keep fighting until the end. Although Sila's doctor wanted to serve Sila's wishes for not invading more near the end, he complied with her niece's wishes, after being threatened of being sued for misconduct of practice/abandonment of patient.

Well, with Sila, at some point the two nieces became active, and very irrational. Sila's sister was a reasonable person; she knew that things weren't going well and we were in agreement. But the nieces who had been absent during all ..., for some reason they became active late in the game, and wanted us to keep fighting and intervene aggressively; ... I can't help but think there was something behind that; but I could not do anything; Sila was unable to support my decisions (Dr Bonus; audio).

8.2.4 Families as gatekeepers

Families' role in protecting the patient and in making decisions on their behalf extended into all activities which involved the patient, even research. It proved to be one of the greatest gate-keeping challenges when I tried to recruit patients. First, the families had to be informed about the research and only if they agreed, they would then let me speak to the patient. Thus, I had to gain the trust of the families before approaching the patient. Nonetheless, when patients expressed gentle feelings about me, my job was much easier.

Today I realised that there is no way I will recruit patients before recruiting families. Liz and Mary the other day returned the consent forms, despite the fact they wished to participate, because their families had not agreed with this. So, with Natasha I decided to approach first the family and it worked. As they were so concerned with the research intrusion, I attempted first to make them engage and relax with me. Natasha also said that she enjoyed my presence, so perhaps her parents thought that this would be a good opportunity for her to have some company. (Reflective diary, 1 month of fieldwork)

8.3 Duty of care: 'do it myself and fight for everything'

Families were "care partners", who were active, caring participants, and whose lives were deeply affected as they shared the illness experience with the patient, making families more than "patient support systems" or members of the care team. Families considered as their responsibility to provide care to their vulnerable member while being in the hospital. Intimate bodily care was perceived to be the family's job in particular. They had, however, not been prepared to cover such a spectrum - from accessing the system, providing basic care to co-ordinating services. Families discovered that they had to improvise in all these areas, as the health care services lacked the relevant facilities and resources. They often complained of having to find their ways by themselves, do everything by themselves.

An overarching theme was the sense of need to 'fight for everything'. There were times in all families that family members felt desperation, frustration, hopeless, because they felt unsupported, not guided through a system which was new to them. They often stated that they felt they had to convince the services of their rights.

It is not only that you have to do everything yourself, it is that you have actually to fight for all of these. The system being incompetent is one thing, but to have to fight for it is too much. I feel so hopeless... it makes me feel so small, squashed under the big stone of bureaucracy. (Con's father, audio)

You fight so hard for your own person, you fight the disease, you fight so hard to keep going and you have the [hospital] system to make it even harder for you. When they told me that Giorgos would not have his treatment today because I did not book his admission since we left last time, I just wanted to sit on the floor and start crying. And the person in the admissions office said to me I should now know for next time. (Iris, Giorgos' spouse, audio)

8.3.1 Filling the gap of fragmented services; 'I have become the servant of the system'

Families often had to mediate between health professionals and services both within the hospital and other health care services and insurance companies. They repeatedly stated that they had not been supported in finding their way through the system, as they had not received information or guidance with regards to the function of services, patients' benefits and aids. Family members of patients said that they had been treated as if they were employees of the health services or the insurance companies, and thus their knowledge about how these work was taken for granted. They had to discover by themselves what was expected from them, and what system gaps they had to fill in.

For example, the families had to take up roles of administration. They were expected to book appointments for the patient at the day care clinic and arrange re-admissions to the hospital. They also arranged the outpatient appointments; organised the routine tests;

brought the patients to the hospital and day care clinic; and delivered the test results to the doctors. They also had to figure out by themselves where the different test rooms in the hospital were and take the patients through, even when they were admitted to hospital (e.g. radiotherapy room, CT scan room, blood tests room).

...Iris [Giorgos spouse] explained that he could not be admitted as she should have arranged this appointment with the administration the last time he had been in but didn't. She was been given a small paper, with the date the doctor suggested for the next admission which she should have given to the administration in order to get the appointment. She said she was desperate, as she had not been explained so and now the chemo would be delayed... She said that Bouda (doctor) told her that she should have understood that this was her responsibility. (Field notes, 5 months before death, morning shift)

This morning (at around 8.30am), they came and they did not know where to go. They [Natasha and her parents] came up to the ward to find her doctor. From there, they were told that they should go to the day care clinic to give a sample of Natasha's urine for investigation. Then she had to do some blood tests, but again they did not know where to go. Usually she came either for the short chemo at the day care clinic and had her tests there, or she was admitted to the ward for the big chemo cycle and had the tests there. This time Natasha came as an outpatient in emergency, so they did not know how to proceed they kept going up and down; finally the blood sample was taken at the day care clinic. (Field notes, 2 months before death, morning shift)

As the care provided was often fragmented, families often took up the role of communicating patients' problems to different health professionals and departments in an effort to co- ordinate the patient's care. Families were called to update new doctors about the patient's history and also to provide information to other specialty doctors who were

called by the patient's doctor for consultation. Sometimes, family members would put themselves forward to negotiate between different doctors in order to achieve the best possible outcome for the patient. Pablo's case can serve as an example of the family's co-ordination of care.

I am the subject of five specialties: oncologists, radiotherapists, orthopaedics, surgeons, one missing? Who is the chief in charge? Who is my doctor? Where should I refer to? Who is the co-ordinator? Such confusion for us and for them. Jella has to be always here to inform each one who comes in about my history and about the decisions which have been made for my treatment. (Pablo, audio 101120)

Jella went today to the orthopaedics by herself and asked them to come and see Pablo; she said she could no longer wait for Dr Bob to request their consultancy, as she felt that there was no communication between the clinics. She said that she could not let Pablo suffer more from his hip fracture and that it was time for them [doctors] to fix it. The orthopaedics came, and agreed with Jella that Pablo needed to be operated. They then informed Pablo's doctor that they could operate Pablo as soon as possible. (Field notes, 4 months before death)

Nonetheless, the doctors said that they were not always happy when families took the initiative to co- ordinate patients' care, especially if this implied incompetency from the doctors. On the other hand, doctors and nurses expected families to co-ordinate issues related to the bureaucracy of services. If families failed to do so, then they were told off and occasionally had been called 'the trouble' ones.

I found Dr Bob and asked him what was wrong with the Polakis [Pablo's surname] family. He said he was upset with Jella; He also said that it was not her role to co- ordinate the doctors and that she had no right to tell him what to do. I asked him if her requests were reasonable or whether she was asking

irrelevant things. He said that the woman knew what she was talking about; and that, in a way, she was helpful; saving him time. Jella had made the orthopaedics come; while if he was sending the referral paper, they would never show up. And he added: but could she keep a lower profile, instead of saying that she could do better? (Field notes, 13 April 2007)

Families not only helped with coordination within the hospital, but also with other services. They complained, though, that they had to revisit services and offices, until they discovered how the bureaucracy worked. They had to personally seek the authorisations for medical prescriptions by the health insurance providers so that they could get patients' medication for free. They even informed and explained to the doctors how they should prescribe medication, which stamps were needed, etcetera, in order for them to be able to take it further.

Ursula's oncologists diagnosed her with cardiac failure caused by the Andriamicine and referred her to the X general hospital's cardiology clinic. When they made the agreement with the cardiology clinic, they asked Ursula to go by herself. As there was no time for Ursula to find her friend, I agreed to help. Hence, I was requested to organise the paperwork of her discharge and admission to the new hospital. We had to take a copy of her file to the cardiologists. We also had to call a taxi to go, as the hospital would not transfer her. (Field notes, 2 months before death)

The doctor prescribes me the injections [chemotherapy], then I have to take the prescription to the central office of the national insurance [IKA]. So the way it goes is: the doctor gives me the paper [prescription] and I go to Omonoia [a square downtown, a bit far from the hospital] to submit it; then I have to go back the next day when they have approved it, and then I have to go to the other office of IKA on Alexandra avenue where the IKA doctor will prescribe it in the

relevant IKA prescription book, and then I can go to the pharmacy to collect it. Then I bring it back to hospital to our doctor who is going to inject it to Fritos. ... yes, this happens every month, as Fritos needs his chemo once a month, unless his doctor feels sorry about me running all over the place; sometimes he prescribes two injections at a time, so that he will save me a month's marathon. And this is only for the injections; imagine that this is repeated for the blood tests at least once a month and the CT scans every four months. (Fritos' wife, Audio 10240)

[Jella speaking to the doctor who brought the prescription for the next chemotherapy] ...no, doctor, it is not right; it needs to be written on the hospital's papers and have the hospital stamp on. They will not sign it otherwise. I have learned now from all the previous comings and goings. I must also go downstairs [administration] and ask them to stamp it properly, otherwise we will not get the medication. (Audio 10234, 40 days before death)

All families claimed that they did not feel it was their role to coordinate patients' care. They felt that they were called to cover for the system gaps and incompetence. They argued that this situation increased their exhaustion, as they had to invest so much of their time and energy in these activities. They claimed feelings of being lost and in despair when they could not figure out how to navigate through the system. When they did not manage to be as effective as they would wish, they felt guilt and anger. A few of the families felt that they had become the problem cases that nobody wanted to deal. Often nurses would be helpful but complain that they had become the secretaries of patients and families.

8.3.2 Managing basic care

Families were actively involved in the care of patients, by providing most of the basic care to their loved ones. They participated by washing the patients and changing the beddings if it was not very complicated. If a patient was bed bound and had open wounds and/or

many drips, the family would sometimes ask a nurses to help. In these instances, usually a health assistant would assist families with the routines.

I made beds with Sofia [health assistant] today. While she was preparing the trolley with the relevant things (sheets, pampers, soap, etc) she said to me that we did not have much work to do, as most of the patients had family members with them. She explained that we don't change the beddings or wash patients if the family is there; we only give the clean sheets and anything else they would need. She said they know what to do and they just ask you to give them what they need. And she was right. We did what she said and relatives did not complain. They thanked us for giving them what they needed. We helped the relatives of two patients because the patients were heavy and they could not help with moving asides. Sofia showed them tips. (Research diary; morning shift; 4 months of fieldwork)

Since all patients were ill for a long time, their relatives were very familiar with small procedures, such as measuring temperature, or record intake-outtake fluid balance. Also, they had been the ones observing the patients for bowel problems such as constipation or diarrhoea, and would report back to the nurses. The main carers, who seemed to be experienced with patients' problems, sometimes did enemas to the patient and feedback the outcome. The families were also vigilant with IV medication administration. For example, they observed the flow of drippings and when an IV medication had finished they reported to the nurses. This was practice even when chemotherapy was administered; nurses often asked family carers 'to keep an eye'.

Roula (nurse assistant) left the nursing office for the thermometer round. I followed her; she said to me that we did not have to do it, unless a patient had nobody next to him/her and could not do it by him/herself. So, the only thing we did was to enter the rooms and ask patients or their carers to measure

temperature; at the end, we came back, just to record it. (Field notes, 8 weeks of fieldwork)

Sila' sister came in the nursing office. She said that the little bottle [IV medication] was over and that she had switched it off; she asked someone to come and connect the next one which was hanging there. (Field notes, 1 month before death, ward Mariza)

The perception of family's duty of care was reinforced by the nurses who often stated that families were their collaborators. Nurses understood that it was the families' duty to perform the 'simple tasks', as they would often call the basic care, and expected the families to respond to their roles. They were prepared to train the families of new patients with regards to what was expected from them. For example, I observed incidences in which nurses had taught families how to wash patients in bed, how to move them or change the beddings in bedbound patients.

The first morning round - at 8.00am - started with Nicky and Roula, visiting patients' rooms with fresh bed sheets. ... When they entered room 305, the wife of X patient said good morning and stood up. She said she would let them do their work. Nicky told her to stay and to help with changing the bed sheets and the clothes of the patient. The carer said he [the patient] looked really fragile, so she was worried that she might hurt him. Nicky and Roula showed her how to turn him on the side, and change the bed sheet from the one side to the other. The patient had also a small pressure sore at the back. Nicky brought the relevant material to treat it whilst teaching his wife how to do it herself. Before we left the room, Roula left the carer with some extra wound covers so that she would do it herself next time. (Research diary, 20 days of fieldwork)

I noticed only a few incidences in which some family members refused to take up such a caring role and the nurses did not welcome their decision. One of the two families

explained to me that they could not cope with the patient's care, because the patient was heavy and his condition advanced; also, they felt exhausted as they had been in the hospital for more than a month. The solution was for them to hire a private health assistant for the morning shift, when most of the basic care was performed.

Nurse Giota said to me that Kula's daughter, who claimed that she could not wash her mum, simply did not want to put her hands on her mum. Giota believed that the daughter found it disgusting. ... On our way to the office, I offered to help with that patient. Giota insisted I should not, because it was about time the daughter started helping with her mother. She said that I could not be there all the time to help and that the patient's daughter needed to do it. She continued saying that they [the nurses] had spoilt her enough, and that she would not let me help her'. (Field notes, 3 weeks before death, afternoon shift)

The majority of the families I followed embraced the role of the active carer with pleasure. They claimed that it was empowering as they had an active tangible role next to their relative. They said that it made their presence important and useful. It seems that performing the various simple tasks helped them organise their time next to the patient. Thus, depending on the tasks that needed to be performed, family members chose their slot within the family rota. Some suggested that they had become the experts of patients' care and that they knew better than anyone how to look after them. The privilege of being the experts outgained their exhaustion; it helped them keep going.

Am so glad I can help her. I love her so much; I would not stand it if there was nothing I could do for her; ... when I bring her home, I make food and she enjoys it; her smile takes all the tiredness away. Besides all these endless hours in hospital without doing anything; I would lose my mind. (Sila's sister, audio 1035)

His father comes in the morning, I cook and do the household, and then I come in the hospital around 11.30am before the doctors' round so I can ask about Con.

Then his brother will come to stay with him and in the evening I will be back. He will need help with shower and toilet, so I should be there. (Con's mother, audio 10181)

You need things to keep going; don't forget we are in this situation for months and months. The fact that I know what Pablo needs and I am the only one that can make sure he gets it, makes me go on; otherwise there are times you want to stop; just stop. (Jella, Pablo's spouse, audio 11582)

However, when families' sense of expertise interfered with nurses' opinion and actions, it brought tension and conflict between them. I observed most of these conflicts when patients were in a terminal state.

Mina's sister asked for a nurse to help her with changing the bed sheets of Mina's bed. She could not help with moving, so her sister requested support. Nurse Maria followed her. The carer kept correcting Nurse Maria, by suggesting her where from to hold Mina, asking her to be more careful with her broken hip, or move her slower because she made her have more pain. She also tried to explain her technique of pulling the bed sheets in a way that Mina would not feel pain. Nurse Maria half the way through told the carer that she knew better how to do these things, and if she wants her help, then she should not try to teach her. Mina's sister replied (increasing the tone of her voice) that she knew better Mina, as she had been the one looking after her all along. (Research diary, Mina's case; 3 weeks before death)

They think they have become experts and they know everything and they tell you how to do your job... They think they know best what the patient needs... But then again, you cannot send them away because you need them. (Nurse Renata, audio1107; 2 months of fieldwork)

The families' confidence of knowing best what the patient needed seems to be influenced by the position families held between patients and health professionals. The families liaised between patients and health professionals for patient's needs/requests. The families mediated in both directions - getting the medical updates and making decisions for the patients, but also transferring patients' requests and wishes. The patients seemed to reinforce this dual role of their families. For this reason, families said that they felt that they acted as the guardian angels of their ill members.

Jella, go and find the doctors; tell them that the pain killers have not worked; tell them that they need to sort this out. (Pablo speaking to his wife, audio 10534)

Maria seemed upset with the lunch brought to her. She shouted that if she saw fish coming again, she would throw up. Her husband removed the tray and calmed her down. He then went to the nursing office and asked them to write down that Maria could not have fish. (Field notes, 3 months before death)

I feel like I am my dad's lawyer sometimes. Who knows best than families? We are next to them 24/7, we know what they want but also have a good picture of their condition. I have been looking after my dad for so many months now; I have become expert. (Sophie, Sotos' daughter, audio 101108)

8.4 Family's decisions of care: a systemic approach

Most of the time, more than one family member was actively involved in the patient care. Family members shared roles and duties while engaging at different levels of responsibility. It seems that the family members adjusted the care roles according to their prior relationship dynamics. To explain better, the members who had a dominant role in the family, most often adopted the decision-making role in the care, while the rest adopted the care-giving role and other supportive roles. The dominant decision-making roles involved co-ordination of care, important decision-making and communication with the

doctors. The care giving and supportive roles focused more on executing tasks, i.e. provision of basic care; day to day decision-making; informing the broader family; doing administrative work such as authorising prescriptions and other back up tasks, such as preparing food for the patient and bringing clean clothes.

In most cases, there was one main carer responsible for the patient care, somebody who coordinated the family around the patient. The main carer was always a woman. If this woman could not fulfil the role, then another woman had to step in. Even in the case that it was not possible for a woman from the imminent family to take up the role, another woman from the extended family had to step in; either a relative or a close friend. The main carers in this study were either the spouse of the married patient or the parent of a younger patient or a child of an older patient. In two cases, a friend adopted the role of the family.

In two cases - Sila's and Tamara's family - where the patients had a dominant role in their family, they maintained control over decision-making until near death. However, they were never given the prognosis, and perhaps this was the reason Sila's family took over decision-making nearly the end. In the first case, the patient had developed a strong relationship with her doctor, had no children, and had maintained independency from the broader family. Thus, discussions and decisions were taking place between her and the doctor until the point she would need to be told of her very poor prognosis; the last 45 days of her life, her sister's family took over all the decision-making. In the second case, the patient was a mother of three adult children and always had a matriarchal role in the broader family. Even though, her doctors informed only her family, her family updated her and followed her wishes whilst she considered her children wishes. In the case of Ursula, a patient who was treated away from her homeland where her partner lived, she was supported by a friend occasionally and thus had to negotiate most of the communication with the doctors herself. However, near the end her wish to go home and spend her last moments looking over the sea was overridden by another friend who

stepped in and changed the route of care. She convinced Ursula to opt for active treatment in a different hospital and became her main carer; that resulted of Ursula dying in the hospital. The friend carer who supported her wish to die at home had to step back.

Within the thirteen family cases I followed, four patterns of family function over time were identified (Figure 8-1):

Primary family members shared roles of care and maintained the same roles until the end. Family members shared decision-making and care giving roles, but one was the co-ordinator. Patient might have the dominant role in the decision-making; dynamics did not change

The main family carer had the dominant role of decision-making and co-ordination. The rest of the family members shared with her the care giving role. When she became weak, a member from the extended family assumed the role of the main carer; dynamics might change

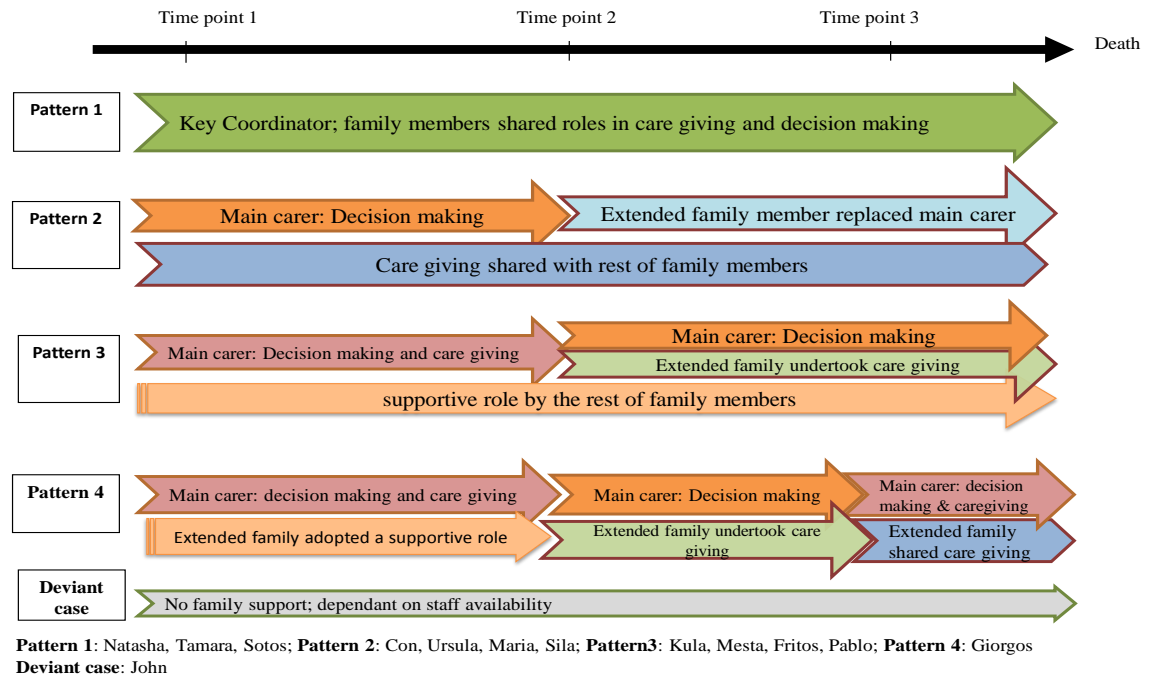
The main family carer had a dominant role both in decision-making and care giving. However, when the main carer became weak, the extended family stepped in by taking over some of the care giving and supportive roles, so that the main carer could maintain her dominant role of decision-making and co-ordination; dynamics did not change.

Patient's main family carer maintained the main role of decision-making over time, but another family member was in charge of the care giving at different time points, due to problems within the couple's relationship. When the relationship improved, the main carer resumed back the roles adopted by the extended family; dynamics were fluctuant (fusion of patterns 2 and 3).

There was one case which did not fit in the above patterns as the patient had no family to support him. He fought to maintain control over choices, but had to submit himself to

the health professionals' choices when no other sources were available. The social service's attempts to support were not effective as they were limited and not consistent.

Figure 8-1: Patterns of family function over time



Two different family cases are presented below illustrating the complexity of the family structure and function over time. The dynamics and the roles selected by the families will be explored for each family exemplar case, with the aim to understand the unique structure of those families, as well as the factors which influenced those dynamics. Sociograms⁴ are employed to illustrate the structure and patterns of family interactions in relation to patient care.

⁴ A sociogram is the sociometric chart that plots the structure of interpersonal relations in a group situation

8.4.1 Tamara's family (pattern 1)

Background information

Tamara was a patient at the age of sixty five, diagnosed with relapsed breast cancer and bone metastases. Tamara was married and had three children. They all lived together apart from the first daughter who was married and had a baby child. The first daughter (age 28) was an accountant while the second one (age 25) a teacher for children with special needs. Her son (age 24) had just received his degree in Mathematics and was offering private lessons to school children. Tamara was a housewife while her husband- one year older- had retired (worked as a mechanic). Both parents had roots from the mountainous region of North Greece, but they had set out their family in Athens. They lived at the west suburbs of Athens (middle income).

Tamara and her family were introduced to the study, two months before her death. I met Tamara and her family in the ward Rallou where she was treated. Tamara was treated in a room with three more patients. I was visiting the room for another patient when I was first approached by the second daughter who accompanied her mother for the most of the day. She was curious to find out who I was, and why I was spending quite some time with some patients. I first explained the study to her, and she then discussed it with her mother. At the next thermometer round, they asked me more about the importance of the study and offered to take part. Both mother and daughter felt they had a lot to share which would help with improving care for the future patients.

At the point of recruitment, the family was aware that a cure was not possible for Tamara. They had been given the remission diagnosis four months before I met them. Six months after the remission diagnosis, Tamara died. Tamara had been treated in the hospital continually for the last 10 weeks of her life and died in the hospital. During that time, her second daughter was next to her most of the time while the other two children and her husband had been visiting her during afternoons- evenings and weekends.

Family relationship dynamics

Tamara had a dominant role in the family and to be in charge of the decision-making about her and her family. As her children would say, even their father would have to listen to her; he would let her drive the family. Her daughter 2 said to me in front of her once:

'... You do not know her from before; mum has been always a very strong woman. She has been the one taking us all out of difficult situations and making this family move on. ... She was also very strict with us but with a lot of love. We all follow her orders. Her nick name is "the general".' (10 May, audio 10283)

Tamara laughed and confirmed that all was truth. She continued saying that always she needed to know what was happening and she was the leader of this family, looking after everyone's best interest. She was the one amongst her siblings having looked after her own parents until their death as well. (Field notes, 10 May)

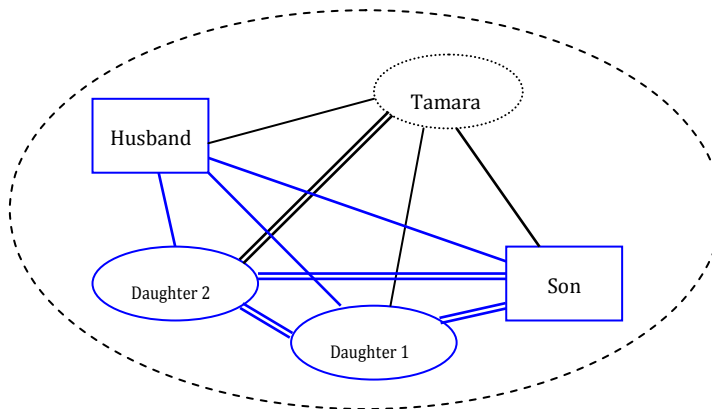
Tamara seemed to be closer to her second daughter, Eleni. She had described their relationship as the emotionally closer and most open comparing to her other children. She argued that she had been involving Eleni in the decision-making over family matters and that both of them had been cooperating in resolving problems; she often referred to Eleni as her right hand (Figure 8-2).

Eleni, is my sweetest child; we have been always very close to each other and I had been sharing my concerns and thoughts mostly with her. She has been my right hand in the family; my operating partner. (Audio 10202)

[Eleni kept stroking her hand, her arm and face.]

D: Your daughter has melted you with her stroke.

T: She always does so; this is my sweet child, the closest to me. (Audio 10250)

Figure 8-2: Tamara's family sociogram

Eleni also explained that she was very closed to her other siblings and that often she had been the mediator between the children and the mother. Moreover, Tamara's first daughter (Maria) was married and had a young child. Hence, she had left the family home for around two years. As Tamara would say, Maria could not be as closely involved in the family issues as she used to be since she had to look after her own little family.

Family roles and dynamics over care and decision-making

Tamara applied her dominant role over the care she received. She said she wanted to have control of the situation, the care choices, and the decision-making of the future steps. She even refused tranquilizers or medication which would help her sleep – she suffered from insomnia- because she was afraid she would lose contact with the environment and thus control of the situation.

She seems to me she wants to have control over her care; she asks to know about everything and seems vigilant: checking the drips if they finish or work well; requesting for a thermometer to measure her temperature; asking about the medication injected to her every time; asking the exact tests which will take place; asking the doctor about his thoughts in relation to what they can do next.
(Reflective diary, 22 May)

Daughter: she does not take the sleep pill to get some rest Des.

Tamara: No, I do not want it because it makes me doze off and then I do not understand what is happening around me. I need to be alert for tomorrow when they [doctors] decide over thoracoscopy. (11 June, audio 10304)

Despite Tamara's position to be in charge of her care, the pattern of communication between her and the doctors involved her children as mediators. The doctors informed Tamara's children - Eleni most of the time - about her condition. Afterwards, information about illness progression and prognosis was shared among children and father and then very carefully passed (all information given without exposing prognosis) onto the mother. Decision-making was negotiated between Tamara and her children; although in many occasions they just followed Tamara's wishes.

Eleni after the meeting with the doctor called her sister and brother and discussed the available options for their mother. Doctor Matthias had said that they were stuck and that they struggled to help Tamara. He said that all efforts of thoracic puncture had either failed or had a minimal outcome, so he was not very positive. He also said that he would like to try a puncture under CT, just in case they were missing the right point, but he could not promise that this would work. He also said that Tamara was exhausted so he was not sure how beneficial this would be to her. He finally said that if the puncture under CT failed, then he had no other suggestions to make. Eleni then went in the room and her mother asked her what the doctors had said. Eleni told her mum about the option of the puncture under CT and also she said they were not certain that it would work. However, she did not say anything about doctors being concerned with the fact that there was no much more to suggest if this would not work. Tamara said she would do it and that she kept her hopes up that this time it would work. She then said that after that she would be much better and she would go home to see her grandson. She asked Eleni to tell the doctor to proceed with this. (Field notes for Tamara, morning shift; 9 days before death)

The family had shared roles around Tamara's care. At that time, Eleni seemed to have the central role of presence and coordination and acted as the link between the mother and the rest of the family; perhaps not only because she was closer to her mother, but also because she could be physically present in the hospital more than the rest of the family. Eleni was not working at the time, and was single, so she had more flexibility comparing to her sister. Thus, Eleni was chosen among her siblings to cover most of the family shift rota; hence she could offer most of the intimate care, and could also be responsible for communication with the health professionals.

Eleni as always sitting on her [Tamara's] right side, held her right hand while trying to wipe the sweat from her chest, beneath the nightdress. (Field notes, 20 May, afternoon shift)

Eleni after the meeting she had with Doctor Madera, she went at the end of the corridor and called her sister to update her. They discussed with each other for about 20 min and then Eleni said to me that they had decided to let their mother know that the results for infection had been inconclusive, which meant that no clear treatment could be suggested to deal with her fever. (Field notes, 13 May, morning shift)

Tamara also seemed to consider the competing priorities of her children; particularly her first daughter's other competing care roles. The first daughter who had a baby was requested by her mother to stay at home to look after her child. Thus, she had obtained the backup responsibilities, i.e. cooking to send homemade food in hospital, wash and send clean clothes for the mother, and look after the father and brother.

Tamara's husband seemed not to be always involved in the discussions over the decision-making (Table 8-1). I saw him in the hospital only in the afternoons and not more than a couple of hours. When I asked the two daughters, they explained that the father had been always soft and weak and that he needed support;

'Dad is soft and kind like butter. He has not been the strong one; mum was always the strong in the family; he just asked mum what to do, especially during crisis. So now, we try to support him and mum has requested so. He does not need to worry about the everyday little things that should be done.' (Daughter 2, 15 May, Audio10239)

Table 8-1: Tamara's family dynamics and roles

Dominant/central role	Tamara
Supportive/peripheral role	Daughter 1
Decision-making	Tamara, and when she gets weaker decisions with children together
Duty of daily care	Daughter 2
Strong female presence	Tamara
Strong male presence	----
Protected members	Husband and 1 st daughter
Prior family structure	Tamara in charge of the family; Daughter 2 had been her 'right hand'
Urban/rural	Urban
Income	Middle

Decision-making of care over time

Tamara's family reached almost always a consensus over decisions making with regards to her care. They seemed to be pleased with the roles each one had adopted. Both of the daughters suggested that sharing the next to mother role and backup role respectively was what exactly they could cope with, taking into consideration their other competing roles. In relation to decision-making, over the last two months of Tamara's life, during which I followed the family, it seems that the family shifted their focus with regards to the aim of

care over time. Also, the different family members seemed to approach decisions differently, even if they shared the same decision (Table 8-2).

Table 8-2: Tamara's family members' focus

	Daughter 2	Daughter1	Son	Husband
Fight to save the loved one	Not relevant at the point I met them			
Fight to keep the loved one longer	Ask for doctors support; try everything they suggest in order to keep her longer	Not active, agreeing with what the rest say	Ask for doctors support; try everything they suggest	Whatever keeps her alive
Chaos/losing the way	Need guidance; feel small and lost What does mum want?	What does mum want?	Want to reassess , get another opinion	Somebody do something, keep her alive
Fight to fulfil loved one's wishes	Not to be in pain, not to be breathless, stay lean and comfortable; Family be together	Brought grandson for her to be happy; Family be together	Try to take her home; Family be together	Not suffering; He withdrew

Fight to keep patient longer; 'We will take her back home with us'

During the first month of observation, Tamara was in charge of the decision-making and the goals of her care, she mostly shaped the actions of her family members. Although staying most of the time in bed, she was extremely alert and spent her time chatting with her children. Tamara was breathless due to pleural infusion because of the local chest metastases. She was getting breathless every time she tried to move out of bed, and she had a couple of acute breathlessness crises. Thus, she was advised to remain in bed, apart from ten minutes, twice a day when she sat on a chair next to her bed. She was

complaining for pain around the chest area and her back which was managed with ibuprofen and codeine.

Tamara expressed her willingness to fight for '*gaining more life with her beloved children*' as she often said. Her family agreed with her and they all worked towards that goal. At that point, her second daughter Eleni was mostly involved. She looked after her mother and communicated the day to day matters with her siblings. Tamara wanted to know what was happening at home as well, and kept giving advice for the rest of the family.

Now, tell me what you cooked for today and tell your father that he needs to pay the next instalments of the loan; it should be due. ... How is Tasos (grandson, age 7 months old)? Has your sister tried to give him proper food? It is about time...
(Tamara, 17May, Audio 10227)

Tamara, although she was the matriarchal figure of the family, had not challenged doctors' preference to inform her family first; she followed the pattern of communication which suggested her children to speak directly with the doctors and then her to be informed by them. Once, she explained that she could not chase up the doctors, being mostly in bed while her children could locate them much more efficiently. Besides, she believed that she was getting all the information from her children. At the time, she discussed medical updates with Eleni in particular and then Eleni with her siblings and father; then she weighted her options; discussed them with her children and ask them to update the doctors with hers/ their preferences.

Eleni, go and find the doctor. You need to ask him when I am going to have the thoracic puncture. It looks like that there is no other option and I want to go home finally, to be with all of you. ... Why do they delay? Is something wrong with my blood tests? Go and ask and come to tell me (Tamara, 20 May, audio 10259)

During the first month, Tamara was positive that she would overcome the crisis and then go home to enjoy her family. She encouraged her family to think similarly. At that time, her doctor hoped that Tamara would be able to survive for at least another six months and go home. Her children expressed similar hopes, counting on their mother's energy and determination. Thus, they fully complied with the doctors' thoughts of trying different options and interventions (local radiotherapy, thoracic puncture). Eleni and her brother supported the view that they should try everything that could give them more time with their mother. Besides, prior experience of overcoming crisis supported their hopes. The rest of the family members did not seem to be actively involved. The other daughter said she would fully agree with her sister while the father kept the principle of following doctors and doing whatever would keep her alive.

According to her medical records, Tamara had been diagnosed with breast cancer 10 years ago. During that time, she had some difficult times with admissions and chemotherapy side effects, but then long times of 'a normal life' where they had almost forgotten the illness as her husband said. It seems that they hope that this is one crisis to be overcome again. (Field notes, 25 May, morning shift)

Tamara's children seem to weight the options according to their mother's fighting spirit. Despite the fact that their doctor had started questioning the more treatment, Tamara's family seem to focus on her wish to fight. Tamara kept encouraging everyone that they would make it through. She seemed to know the influence she has on her family, and even though no improvement was apparent, she asked Eleni to be more positive when reporting to the family.

Tamara: I am fighting today very hard, I am waiting for tomorrow...
Daughter 2: She fights very hard today, indeed. Do you know what she can be if

she wants? She is 'a wild beast'. She has been a fighter all of her life, right mummy?

Tamara: (smiles) we will go home soon and sit at the balcony and play with little Tasos [grandson]. You shall see; now, put a smile on your face; don't tell your siblings how hard our night was. (Audio, 13 May, 10204)

The delay of Tamara's appointment for the puncture the increase of breathlessness episodes seemed to influence the family's change of focus. The appointment of having Tamara a thoracic puncture under CT scan was arranged for after ten days. The reason was that the hospital was left with only one CT scan machine available as the second broken one, was not yet repaired. Tamara's intervention was not assessed as an emergency. However, during those days Tamara had a couple of break through breathlessness which made her more fatigued.

Tamara had a difficult night last night with uncontrolled breathlessness and pain. Eleni was sitting next to her. Eleni's eyes were full of tears. Tamara looked for her hand; she turned towards Eleni and reminded her that they had been in such a difficult situation before, and always had made it. She asked Eleni not to let her spirit down and be positive when reporting to the rest of the family. (Field notes, 25 May, morning shift)

Eleni expressed clear concerns to me about her mother's suffering and questioned the agreed decisions. It was the first time I recorded Eleni's doubts. In tears, she explained that she had been frightened by the fact her mum was desperate for help and that nobody could help her. She seemed to start outweigh the benefits of the interventions as to her mother's suffering.

Death seems possible- chaos, losing the way: 'we will not escape this time; we will lose her; what do we do now?'

Ten days before Tamara's death, the family started considering that death might be unavoidable. During those days, Tamara's children stayed in hospital longer while spending time next to their mother. Both sisters were involved in the intimate care. All of the three siblings tried to attend update appointments with their doctor, rather than letting Eleni do the job. They seemed stressed and often asked my assessment with regards to whether their mother would make it this time. The children were all actively involved while some of the backup tasks had been delegated to members of the extended family.

For two days now Kostas, Maria and Eleni come every day to hospital and stay next to their mother. Maria said that the grandson is looked after by the mother in law who is also helping with cooking. The medical meetings take place with all of them together. They look worried and ask everyone [nurses- doctors and I] how they think about their mother's condition. (Field notes)

Dr Mathias said that this change of the family's pattern of involvement influenced his way of thinking with regards to Tamara's care decision. He explained that the change of intensity of the family's presence and the level of involvement by all members helped him realise that Tamara's condition had changed and that she probably was moving to the next phase.

Do you see them? They all come together now, and they all stay next to her. They feel it, they realise it that Tamara will not probably go home again. I think they try to spend more time with their mother... you know, this makes me feel the change. I mean that Tamara will not make it. They had been positive that they will overcome it as before; I did too. But now I am not sure either. (Dr Mathias, Audio 10305)

At this point, the different family members disagreed with the decision-making and also the focus of care. The radiotherapy was ruled out for the time being; Tamara was too weak for this, but the question was whether they should try more punctures in order to remove some of the pleural fluids. They approached the matter differently aiming some of them for extending life and some for relieving suffering. Eleni who had spent most of the time next to their mother had started questioning any interventions and found it particularly challenging to make a decision. She expressed feelings of stress and desperation, and a sense of lost, weakness. She wondered what the benefit of more intervention would be, and although she hoped for extending life, she considered options of relieving Tamara's suffering. Her brother seemed to approach the issue more rationally and with the hope of maybe gaining more time with their mother. He wanted a second consultation, aiming at gaining more available options and ways forward. He hoped that an effective puncture would unblock space for the lungs, and that would help Tamara to turn the corner. Maria cried a lot and complained she had not been enough with her mother. She said she would trust Eleni's opinion, but she wanted the option which would give her more time with her mother. Their father, although being hardly present, suggested they should do whatever doctors say and try anything to keep Tamara alive. Both Eleni and Kostas expressed the need of supporting their mother's wishes and not try to take the full responsibility of the choices.

Tamara kept fighting for the puncture, and requested all possible interventions which could unblock her lungs. Thus, the decision was to continue with another attempt of puncture. Her children interpret her attitude as of wanting more life. Despite what each one of them wishes for, they decided to support the mother's clear option.

Tamara: I am waiting to go for the CT

Researcher: What is going to happen?

Tamara: what will they do to me, you mean? Puncture to my chest

Researcher: what is going to happen with the puncture?

Tamara: If it works, I will be so much better then. I will rest and the pain will be loosened; my child you cannot imagine how bad I feel with all this pain and lack of breathing

However, it is unclear whether Tamara's priorities had changed. Tamara might have made those requests, hoping to be relieved from the pain and the dyspnoea, rather than hoping for more life.

I fear that this time we will not escape; that she might not make it. But how can we stop fighting when she is fighting so hard? She wants to live; we cannot tell her to stop. (Eleni, Audio 10280)

I tried very hard to approach and speak to Tamara's husband. I observed him over evening time, coming for about one or two hours, spending most of the time outside of the room, in an open space, outside of the ward Rallou. He seemed to avoid contact. His children encouraged him to stay away. They explained to me:

We do not let him stay next to mum for long, because he starts crying and this does not help. Then mum asks us to send him home, and she worries about him and keeps asking us to look after him.

When I asked his opinion and thoughts of the situation, he avoided expressing an opinion and left most sentences uncompleted. He said it was always Tamara making the decisions; he could not now make decisions for her.

Husband: Whatever science says, me what can, what can I say?

Researcher: So do you think she would be ok to try tomorrow the puncture?

Husband: I don't know. I don't; [long silence] maybe? What do you say? I guess so? If it is to have the intervention; [long silence] local anaesthesia? I mean not to be too heavy [long silence] the woman [long silence] she will be ok, won't she?

Researcher: What do you think it is more important for her at this point?

*Husband: She is a strong person, she holds on. Maybe she wants to stay... or not.
I don't know ...to say. She in charge; ... I cannot decide for her.*

Supporting mother's wishes and with dying: 'we need to help her prepare'

Tamara and her family seemed to have placed all their hopes on that chest puncture effort under CT scan. The negative outcome seemed to make the family and Tamara accepting the imminence of death. It seems that it triggered the preparation of dying as shown in the research diary below.

The puncture took place four days before her death. That day, her children had all come in the morning to wish their mother good luck with the intervention. They kissed her and hugged her when the porter came to transfer her for the intervention. When she returned back to the room, she seemed exhausted. She kept her eyes closed, and the only thing she said was '*it didn't work*'. She kept quiet for almost all day. She refused to engage to discussion with her children when they tried to speak to her. She refused any food or liquids. Some hours later, her daughter Eleni said to me: '*That was it. And we really hoped it would work*'. Dr Mathias came back in the office, looking upset. He threw the files on the table and said '*Dam, completely failure; as if life does not want Tamara any longer; there is nothing I can say to the family; we tried everything, but nothing worked*'. I felt it was a very heavy day. I recorded only a few short dialogues in relation to pain killers and oxygen therapy.

The next day Tamara engaged with communication. She seemed to engage in a farewell process. She asked to see the nurses who had looked after her, and she thanked them for all their efforts. She did the same thing with Dr Mathias. She told him that he was a good doctor and compassionate and that he would have a terrific future. Doctor Mathias could not hold his tears while holding her hand.

The same afternoon Tamara requested all her children to stay next to her while sending her husband away. They spent the whole afternoon evening chatting. The children

updated her with everything in their lives (e.g. Eleni spoke about a man she dated) and decided to bring her grandson in the hospital.

The next day, Tamara's children asked Dr Mathias to remove if possible all catheters and leave only the necessary ones. They asked for no more interventions for their mother. The doctor agreed. The drainage catheter from the puncture was removed. That afternoon Tamara requested her children to prepare her and the funeral the way she wanted. She requested specific clothes and shoes. Her children asked me not to leave as they found extremely hard to deal with it. I stayed to help with preparing with their mother.

8.4.2 The case of Giorgos' family (pattern 4)

Background information

Giorgos was a patient at the age of forty one, diagnosed with Large Cell Lung Cancer (LCLC). Giorgos was married to Iris (same age as him) for three years, at the moment of diagnosis. Giorgos was an ironmonger and Iris an employee of a local supermarket. They had no kids, despite their efforts. They lived in a sub-urban area outside of Athens (15 miles away), near Iris's parents. However, Giorgos often stayed at his mother place during the course of illness, especially after hospital discharges, as her home was near the hospital.

Giorgos and Iris were recruited to the study, eight months after his diagnosis and four months after he first came to the specific hospital for treatment. Giorgos had an operation in an effort to remove the lung tumour and followed five cycles of chemotherapy and two cycles of radiotherapy. The last month of his life, he tried to enrol in an experimental protocol in a private hospital. Since I met them, Giorgos lived for 26 more weeks. During this time, he had only seven weeks with no contact- inpatient or outpatient- with the hospital. His last admission lasted for three weeks during which he died.

I met Giorgos and his family in the ward Mariza, while admitted for chemotherapy treatment. At that time, Giorgos was trying to convince the doctors that he was not neurotic and instead his neuropathic pain of his right arm was true. I spent sometime next to him, while accepting his truth and helping him to dress up. The next day, during the thermometer round, he and Iris

expressed interest in knowing more about me. When I explained about the study, they showed interest. Two days later, they enrolled to the study.

Family relationship dynamics

Giorgos was close to his wife and his mother. Both of the relationships were conflicting. Giorgos had complained that Iris was trying to dominate him and that his mother tried to patronise him. His mother and his wife had a distant relationship whilst the accused each other for dominating Giorgos' attention and love. His mother had not approved Iris as his wife whilst Iris's parents had always been very supportive to them.

She took him away from me and she makes sure there is no enough space in his life for his mother. (Giorgos' life, informal conversation recorded in field notes, 4 months before death)

I cannot stand her anymore. She treats me like a child. She even wants to feed me in the mouth. It is even worse when I go back to her place. She is not leaving Iris and me alone, not even for a second. She spies our discussions. (Giorgos, Audio 10177; 3 months before death)

Giorgos and Iris seemed to rely on each other and to share their life decisions. They were trying to create their own family when Giorgos got diagnosed with LCLC. Giorgos explained that he was very close to Iris and had not maintained close relationships with his own family as they had not approved of Iris, especially his mother. Iris's parents were supportive of the wedding and thus had been closer to them. Giorgos and Iris built their house, on a piece of land, which Iris's parents had offered them. Although they tried for a child, they considered separating the past year. Iris claimed that Giorgos had not been co-operative or sensitive towards her needs, but instead rather abrupt and aggressive. Giorgos on the other hand, complained that Iris wanted to dominate him and make him obey to whatever she wished.

She should push whenever it is necessary, where there is really a problem. This is stupid, I am not a child. Do this, don't eat that. I told you not to move your hand, etc. She is after me with every little thing; it has to happen what she wants, not what is really necessary. (Giorgos, audio 10196; 5 months before death)

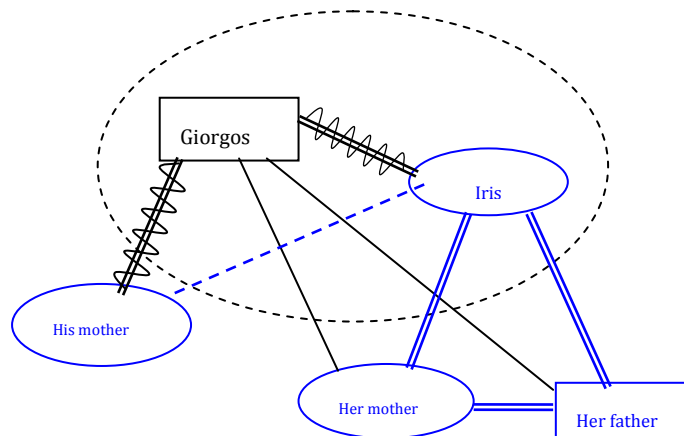
I try so hard for him, and he does not appreciate it. I am saying what I am saying [what I say] for his own good, but instead he is abrupt and rude. I sacrifice so much for him, but he only thinks of himself; never about me, what needs I have. (Giorgos' wife, audio 10185; 5 months before death)

Nevertheless, when he was diagnosed with cancer, they decided to stay together and fight against it. They suggested that the illness became the cause of their reunion. Nonetheless, at different time points, Iris expressed feelings of being trapped in this relationship as she felt guilty to leave him, particularly when she was informed about his prognosis. Giorgos on the other hand, said occasionally that he felt Iris was not staying with him because of love, but because she was sorry about him; that made him feel angry.

My life passes by while I am taking care of Giorgos; and he will die but I will stay behind with no more youth to make my life again. ... Before he got ill we had separated for some months and I was planning to divorce him. But now I cannot leave him. (Giorgos wife, audio 10185; 5 months before death)

The dynamics of the family were challenged by the fact that Giorgos' mother adopted a more active role in the family care while becoming part of the family rota in the hospital. In addition, she offered her home for Giorgos to stay after being discharged from hospital, since Giorgos and Iris's house was 15miles away from the hospital. Existing problems in their relationship seem to result in lots of tensions and fights (Figure 8-3).

Figure 8-3: Giorgos' family sociogram



Family roles and dynamics over care and decision-making

Iris was responsible for Giorgos care most of the times. When their relationship was challenged, Iris withheld from the intimate care and maintained her role in decision-making. The intimate, basic care was delivered by his mother during those times. However, it seems that none of them had control of the treatment options for Giorgos. Doctors seem to make the decisions of care for Giorgos and expect from Iris and Giorgos to follow. Iris had complained that she was given orders, and that she was never explained what were the care plans, or the prognosis; something she needed to know in order to make her decision of staying next to her husband longer or not.

I need to know how long we have to go like this; I need to see if I can cope or I should give up on him. (Giorgos' wife, audio 101119; 3 months before death)

Nobody seats to discuss with us. They just give me abstract orders which I then need to follow without even understanding why I am running behind them. I don't know what to expect, how to help him. I am so lost [she was crying] (Audio 10172; 4 months before death)

When it was time for them to go, doctor B. gave them with the many other papers a little paper for the next appointment at the day care clinic. Iris looked at it and started saying something like why that was needed and if another day would be possible. Doctor B. interrupted her and said 'when doctors say you need to come this day, you listen and obey to what they tell you; because what they suggest is for you best. (Field notes, Giorgos discharge after chemotherapy; 4 months before death)

The family's difficulty to collaborate smoothly seems to have influenced the communication with the doctors and the decision-making of care which was controlled mostly by them. Doctors explained that they could not trust Giorgos' family that they were able to cope with the demands of Giorgos' care and for this reason, they thought they could not share responsibility with them. They said they could not trust family's collaboration, as they were not united as a family and they had failed in dealing with administration procedures. Also they thought that the frequent fights between the couple indicated difficulty in coping with the stressful situation of disease progression. Thus, they decided to choose carefully the information given and focused on instructing the relevant tasks.

The more you tell them, the more they ask. But yet they do not manage to work well. They are a problem case, so the less the better. They fight like stubborn kids, how can you trust that they are serious and they will help? They have missed this admission, because simply they did not taken the papers we gave them down to the administration office. Better tell them what to do and keep it simple (Registrar B, audio 10167)

The family's plans in relation to end of life were not encouraged, despite the repeated requests of Giorgos' wife with regards to his prognosis. Only two months before his death, an over optimistic prognosis of two years was offered, with the aim of supporting

her. Yet, such news was not welcomed positively by Giorgos' wife. She explained that she felt she could not cope with this severity of disease for much longer; that she was exhausted and also would not want so much suffering for Giorgos since he would die anyway.

Iris asked again today how long Giorgos still has to live. Dr D. replied that he will live for maximum to two years. She then explained that they could not do much as Giorgos went to them quite late; the tumour was more than 6cm when they accepted him in the hospital. ... Dr D. explained to me that she did not want to make Iris panic and stop co- operating. Iris though said to me she was not surprised as she could see that Giorgos was deteriorating. She said though she did not know how to feel or think as the suffering for both of him would not go for very long but not short either. (Field notes, discussion between Iris and Dr D; two months before death)

It is two years, it is not very short. In what should I invest now? I would tolerate this and be patience for what? He will die and I cannot take it much longer. Another two years of such suffering? ... If that's the case, I need to find then a job soon; I am in the air. (Giorgos' wife, audio 101114, 2 months before death)

Decision-making over time

While Giorgos' family did not participate in the main decisions of treatment plans for Giorgos, they undertook the responsibility of basic care and the expected co- ordination of care. Iris held the decision-making of coordinating their life around treatment; handling the emergency events which sent them twice to the A&E of a general hospital and in nearly the end of looking for alternative places of care and other physicians.

Giorgos' mother responsibility fluctuated depending on the relationship of the couple. During the crisis periods between the couple, Giorgos' mother took over the responsibility of the basic care and made decisions around his basic care (washing, food provision, paying attention to his drips, reporting symptoms)

When I walked in, Giorgos was seating at the chair, whilst his mother helped him to change his pyjamas. ... She told me that she recorded his temperature since morning and gave him Paracetamol twice because he had fever of 38.5. Iris was not there. Giorgos told me they had a fight again and she had left without saying anything. (Research diary, visit Giorgos-afternoon shift, 4 months before death)

Giorgos' carers (wife and mother) were reactive to his attitude and coping state. Giorgos' family was the only one that had not been disclosed the truth of the prognosis by the doctors. Critical events during Giorgos' journey seem to trigger transition to family's focus from cure to care and eventually hoping for a peaceful death.

Table 8-3 presents the events and changes over time which seems to influence the focus of the family and the decision-making.

Table 8-3: Giorgos' family function over time: health state, critical events and decision-making

6 months before death (Feb) Undiagnosed neuropathic pain Couple's relationship in crisis	Symptoms: Giorgos presents with neuropathic pain. Health professionals think he is neurotic, attention seeker, and do not treat it. Family dynamics: Giorgos and Iris fight a lot. But they are focused in saving Giorgos' life. Iris aims for his cure in order to have a child from him soon. Decisions: Health professionals do not trust Giorgos and Iris and dictate treatment options: active treatment with chemotherapy and radiotherapy.
4 months before death (April) Increased treatment side effects; complications with infections Family questions active treatment	Symptoms: critical events; Giorgos suffers from chemotherapy side effects. Two incidents of infections which delayed treatment are not treated promptly, according to the family. He then states thoughts that treatment is poisoning him. He says that his body is not getting any better. Change: Giorgos starts focusing on getting symptom relief and on reducing treatment. He influences Iris to support such a direction. Decisions: Iris negotiates with the doctors the active treatment plan.
3 months before death (May) Fatigue Increasingly more time in	Symptoms: Giorgos feels fatigued and tired of travelling to hospital. He increasingly requests for the opportunity to spend time at home nearby the sea [summer settles in.] He expresses thoughts that he might die. He bases these thoughts on the fact that he constantly feels worse rather than better and also on the words of the radiologist who told him that his lungs are not performing well.

<p>the hospital</p> <p>Wife gets in-tuned with husband wishes</p> <p>Care plans challenged against quality of life and symptom control</p>	<p>Family dynamics changes: due to fatigue, Giorgos has to spend more time in his mother's house which he does not prefer. His wife is not welcomed there and thus they do not spend much time together outside of the hospital. He says that he re-evaluates his life.</p> <p>Decisions: to give priority to his marital relationship. Iris becomes very receptive and seems to get in tuned with his wishes. She commends positively on the change of his attitude and behaviour and expresses her wish to stand by him. Both Giorgos and Iris seem to consider both scenarios of him getting well or die. For a month period they express thoughts on both scenarios and prepare for both.</p> <p>Decisions: Iris changes focus to work on sharing happy moments with Giorgos. She invests on reducing the hospital visits by paying for services offered nearby their home.</p>
<p>2 months before death (June)</p> <p>Episodic breathlessness</p> <p>Family decision of not extending life; focus on symptom control</p>	<p>Symptoms: Giorgos develops episodic breathlessness. Iris expresses concerns of a poor prognosis.</p> <p>Change: Giorgos' suffering and Iris' exhaustion seem to influence a change in her wish for not extending life, since the outcome is death. She actively asks for an estimate of life expectancy and requests care which control symptoms. She is given a prognosis of 2 more years which she does not welcome.</p>
<p>A month and half before death (July)</p> <p>Uncontrolled symptoms</p> <p>Family makes the decision to ask medical help in a different setting</p>	<p>Symptoms: Giorgos suffers from uncontrolled breathlessness and pain. Doctors say that they cannot help; not much more to do. Giorgos' family say they feel lost and desperate.</p> <p>Change: Iris takes the lead and decides to ask for help elsewhere. Iris also seeks for an alternative place of care and doctor, aiming at controlling his suffering. They visit a private hospital after the suggestion of a friend. Whilst in discussions with the new doctor, Giorgos' pain and breathlessness get considerably worse.</p>
<p>A month before death to death</p> <p>Severe episodic breathlessness and pain. Giorgos is admitted to the hospital and stays until death</p> <p>He realises dying</p> <p>Family is aware of the dying; they unite to work in relieving Giorgos.</p>	<p>Symptoms: Pain and breathlessness are not controlled. During severe breathlessness and pain, the family requests admission to the hospital. Giorgos is constantly attached to the oxygen. Pain management is intensified. Giorgos gets bed bounded due to thoracic pain and dyspnoea. He screams for symptom control; the nurses avoid entering the room as they feel helplessness to support, particularly with the severe breathlessness episodes.</p> <p>Family dynamics: Both Giorgos and his family focus on symptom management. Giorgos accepts the imminence of death. <i>'I know I am going no matter what you say. My body is leaving me'.</i></p> <p>Doctors inform the family about the imminence of death. It seems that both Iris and Giorgos' mother decide to work together. The family focuses on basic care. The wife assumes the day shift and the mother the night one. Iris maintains control of the updates and the communication with the health professionals. Both carers aim for the patient's relief. They discuss the option of getting Giorgos home. Family seeks reassurance that they have tried everything for him and that this outcome is because nothing else can be done to control it.</p>

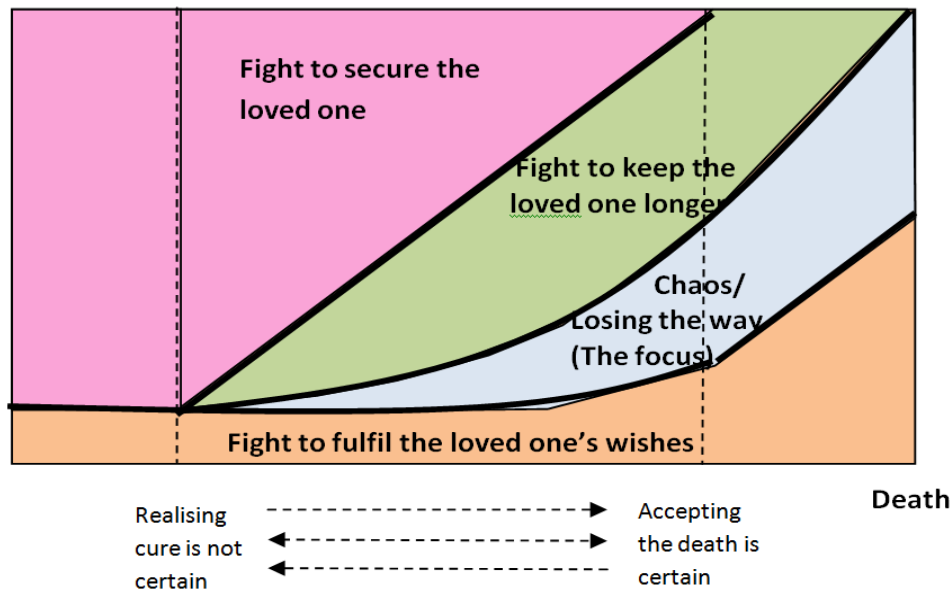
<p>Fifteen days before death (August)</p> <p>Family chooses for a hospital death</p> <p>Giorgos initiates dying preparation; family follows him</p>	<p>Symptoms: persist, relief is not succeeded.</p> <p>Decisions: Iris declares that she cannot cope with Giorgos dying at home. She says to the doctors that she cannot deal with his symptoms alone at home. Giorgos withdraws from the initial requests.</p> <p>Family dynamics: Iris and Giorgos seem to become emotional. He asks forgiveness for the troubles of their relationship and expresses gratitude for her love and support. Iris blocks such discussions initially, but with Giorgos persistence, she then engages. She openly expresses her love. Giorgos also reconciles with his mother. His mother laments next to him.</p> <p>Change: Iris wishes for a quick death, so that he will stop suffering: <i>'anything that will make him not suffer anymore'</i>.</p>
<p>Last day (August)</p> <p>Giorgos performs dying rituals: farewells and request of favourite taste</p>	<p>Giorgos' symptoms seem to be eased. He initiates farewells and asks for his favourite drink. Iris misses the meaning of Giorgos' request for his favourite taste and refuses him the drink. Giorgos promises eternal love to Iris and after-life reunion. He sends her home earlier than usually. Iris believes she will see him the next day. He calls her later to tell her that he does not suffer anymore. He dies two hours later. His mother witnesses his death.</p>

8.5 Factors influencing family's decisions of care over time

Different factors seem to have influenced the family decision-making over time. Four factors were identified to influence families in their decision-making; the point of the illness trajectory and its awareness; the family dynamics; and the patients' wishes. The place of living (urban/rural) might have also been influential. Different factors seem to take priority at different points of the trajectory. Thus, I present them within the different phases of the family trajectory. Four significant stages of family trajectory were identified (Figure 8-4):

1. Fight to secure the loved one (active treatment);
2. Fight to keep the loved one longer (intensified active treatment);
3. Oscillating between extending life and accepting dying (elements of palliative care might be introduced);
4. Accepting the certainty of death (final days of the patient's life and doctors' presence withdrawn).

Figure 8-4: Family's trajectory and decision-making



8.5.1 Fight to secure the loved one

During the initial months of observation (3-6 months prior to death), patients' families believed that there was the option of cure for the ill family member. Hence, the decision-making of care was focused on treatment as prescribed by the doctors. All families at that point were advocates of the health care team and their efforts were fixed in making sure the patient members comply with the medical suggestions. During that period, patients did not object care plans.

Dr X is taking care of her; he knows what treatment we need to follow. He gives orders to everyone; he makes me feel safe. He checked the tests himself; he knows what he is doing. We will listen to what he says (Sila's sister, audio 1029, 4 months before death)

... She asked him to help her by lifting his back and change position. He turned to her and said 'Jella, I am in pain, leave me alone'. She said 'I want to make sure it is ok, because you have started developing pressure shore at the back. Doctors said we should be careful and that the last thing we need now is for the wound to

get infected. They asked me to look after it; you need to do what I say, what they tell us. (Recorded conversation in Field notes, Pablo and his wife, 5 months before death)

Families started realising that a cure was not certain when doctors broke the news of a metastasis or a non reversible complication. Family members expressed a need of protecting the ill member more as they were not safe anymore.

I have starting thinking seriously that we might lose Ursula. Dr Ard. told me that the treatment has affected her heart and that this cannot be sorted [toxicity from chemotherapy with Adriamycin]. He said we need to stop this treatment, but this is not good for the cancer. (Ursula's friend, a month before death)

This is it. The cancer went to the bones. Doctors saw today the CT scan. .. Dr B. said we have no chance to kill cancer now... We do not give up, we will fight to keep him as much as we can with us; but eventually... [She cried]. (Pablo's wife, 4 months before death)

8.5.2 Fight to keep the loved one longer

When families understood that a cure was not certain, their goal shifted to extending life. Doctors' encouraged such direction and reassured them that they would not give up, but instead continue fighting. The decision was to continue active treatment in most cases and the efforts of extending life became even more intense. Families accepted to continue with different regiment protocols and combined treatments (e.g. chemotherapy and radiotherapy). Such an attitude was adopted by Con's family when their doctor informed them about his liver metastasis.

... I understand his situation. But we will not give up on him. We will stick together and fight to keep him with us as much as we can. Is it a month more? Then it is a month more. It is the time to fight all as one more than ever. Dr E.

stressed the importance of not getting disappointed. We will prove him our love.

I will never give up on him. (Con's mother, audio1032, 2 months before death)

At that stage, data revealed the first incidences of conflicting thoughts by families with regards to the treatment decisions. They started re- considered the attitude of fighting cancer. As Natasha's father said two months before her death, the argument of keeping the patient compliant and patient started losing its significance as cancer would not go away. Pablo's wife started questioning the initial care plans when she was informed that cancer had metastasised in his left hip. She said that they needed to re think of their life as the illness, and the hospital treatments proved to be more than a bracket/ interruption in their life. Instead, they would need to incorporate it as part of their life.

I do not know what is best now; what is the point of telling her to be patient with all this mucositis and bare more treatment? I keep telling her that it is only for short period and then she will be better, but now we know it will not happen.

(Natasha's father, audio, 45 days before death)

... Things are not going as we hoped, we need to re-plan. ... It got out of hands.

We are stack this time. Now we need to live with this; it will not go away ... Do you think we should continue with all this chemotherapy? (Pablo's wife, audio

10183, 3 months before death)

8.5.3 Oscillating between extending life and accepting dying

Whilst doctors maintained a focus on aggressive treatment, families seemed to question the existing plans and oscillated between the guidance of doctors for active treatment and patients' preferences. Although they still considered themselves as part of the care team, they started advocating stronger for the patients' wishes.

Dr Effie said he needs again colostomy and radiotherapy. Con told me if that was happening again he would jump from the roof. Dr Effie said she wants to

continue. They can remove some part of the colon and that she could try also some new drug; that she can give him more time. I said no, enough. It is more important to keep him happy now. I don't want to put him in more suffering. If he says no, I do not want to push him any longer. (Con's mother, audio1018, 3 weeks before death)

The period between the awareness of the incurability of cancer and acceptance of the death certainty, families fluctuated between wishes and choices from fulfilling patient's wishes, such as refusing new treatment options and making choices to comply with medical orders and fighting for extension of life by accepting aggressive treatment.

I know things are difficult and that Natasha is tired and has lost her courage to continue fighting; but as Dr X said, cancer might have won this battle but not the whole war. We will try harder. The next battle is ours. (Natasha's father, audio12002, 1 month before death)

The conflict in the preferences derived from the different agendas the family and the patient might have. For example, family members, emotionally dependent to the dying person, resisted the acceptance of dying.

Maria [Sila's sister] had an argument with Sila's husband today. When she opted for more treatment, he asked her if she really preferred Sila to live longer but in such condition and suffering. Maria said that Sila was the only family she had besides her own and she could not let her go. (Sila's sister, research diary, 2 days before death)

I cannot stop fighting for him. I cannot think of my life without trying for him. No meaning would be left for me to keep going. (Fritos' wife, audio3423)

On the other hand, uncontrolled symptoms and patients wish to let go, directed families towards stopping treatment and moving towards accepting dying.

We have been suggested to move to another hospital where a doctor wants to try something new, experimental; but it might work. I told Giorgos, but he said he had enough. I cannot see him with such dyspnoea. My heart breaks, but I cannot ask him to try more. (Giorgos' wife, audio 11110)

Family's physical and emotional burden from the long periods of care, the long periods next to the patient; the emotional intensity that accompanied the patient deterioration seemed to take its toll in the end.

I feel guilty, but I feel I cannot continue like this. Either he should get well or die. This lingering has completely exhausted me. I am sorry I say this, but honestly, I feel I am collapsing. I have become so touchy; my husband says he cannot tolerate me anymore. And my poor children, I have not patience for them. (Sotos' first daughter, audio 101488, days before death)

Families varied in their process through the stages of their trajectory. Some families moved from fighting and aggressive treatment straight to the dying phase whilst others went through all stages. Also, the length of time staying in each stage differed amongst different families. The attitude and coping of the decision-maker of the family influenced the transition from one stage to another. For some families, it was a smoother process comparing to others. The rapid decline and the uncontrolled dyspnoea or pain intensified the chaotic period where the focus was lost. The only non negotiable stage was the death acceptance and the dying during the last days of life.

8.5.4 Accepting the certainty of death

Most of the families showed accepting death and dying near the end (average time two weeks before death). Acceptance of death and dying was observed near the imminence of death. The awareness of dying came from their observations of the patients and the changes they saw on them. Patient's withdrawal of communication and food; fatigue; and in a few cases uncontrolled dyspnoea seems to trigger families' insight of patients' dying

phase. During the last days, all families commended about the patient 'letting go', or 'giving up'.

She is not well. She barely talks. She tries to hold on only for us, I think; do we torture her? Maybe it is time to let her rest. (Sila's sister, audio, 3 weeks before death)

He stopped asking any more questions the doctors; Con who has been so assertive and wanted to know everything. I can tell he is giving up. (Con's mother, audio 10168, 1 week before death)

She is eating like a bird and has lost completely her interest in food. (Natasha's mother; audio 10109, 2 weeks before death)

As there has not been any preparation for the dying, that period was extremely intense and compact. Most of the families went through a phase of being completely confused and expressed thoughts of 'loosing the way' while they reported feeling of desperation and hopelessness. Such feelings were intensified in the cases that patients experienced uncontrolled symptoms.

I bump into Jella, on my way to see Fritos. When she saw me, she grasped my hand and pushed me in the corner of the corridor. She looked much stressed. Her voice was loud and tense; she spoke nonstop... She said to me that Pablo was in extreme pain and treatment given to them was not working. She started crying and saying she did not know what to do. She said she knew he was dying, but there should be something to help them. She said she had never felt so small and so lost. She squeezed my hand painfully hard. (Field notes, meeting Pablo's wife, 10 days before death)

Giving priority and space to the patient seemed to give a resolution to the conflict between fighting for more life and letting go. The family's focus was on patients' needs and

wishes. Fulfilling patients' wishes were described to be the final act of their relationship; a proof of love and dedication. Also, symptom relief became one of the main goals for the family.

He said he wanted to live by himself; we have a second small flat, we asked the tenants to go so that he can go there. We want to make him happy, to experience what he wished. He looks so happy. HE is going there for some hours; he has his own space and when is ready he comes back to us. I wish we had done this earlier; we thought we would have more time together, but it seems not. (Con's mother, audio 10157, 4 weeks before death)

During the last days of patient's life (a week to hours before death), a distinctive phase seemed to exist. It was the time of preparing for dying. This phase was initiated and led by the patient. Families seem to understand the signs and in most cases, they tried to help patients with the dying preparation, and participated in the dying rituals (see more in Chapter 9).

Dad wants to die back in our home, up in the mountains. The whole family will spend the last moments together as he wishes. ... I know he is too fragile, that is why we have already arranged to take him up with a helicopter. (Sotos' son, audio 10156, 2 days before death)

Some families had started speaking in the past tense for the patient during the last days before death. They also recalled memories from their life with them; seemingly a process of reminiscence ...

Sila was a very useful person to her family and society. She was very active and always trying to help people. ... I cannot believe that she is dying; am losing my only sister. (Sila's sister, 2 days before death)

You should have met him before Des. He was such a kind and wise man. The entire village was going to him for advice. He cared about all of us. He never criticised anyone; only helped when he could. (Sotos' daughter 2, audio 10148, 5 days before death)

In some cases, lamenting was also observed before death. Nurses suggested that this was an indication that the patient was dying. Giorgos' mother was a clear example of mourning before death, whilst sitting next to him and stroking his hand.

Oh, my lion, how you were and how you became; where is your strength? Where did your hair go? I did not have you enough. (Giorgos' mother, lament recorded in the field notes, 3 days before death)

8.6 Summary

This chapter has focused on the family's role and involvement in the patient's care. Families perceived their role to be actively involved in most aspects of patient care. This ranged from basic nursing care, such as feeding and washing, extending to decision-making on behalf of the patient. Families became an extension of the health care team. Families functioned in different ways, and four patterns of differing roles were described. Families created their own way of functioning and supporting their loved one throughout the illness trajectory. Providing a stable foundation in the unpredictable world of illness remained paramount to the patients' well being. The family's role in decision-making, whilst ultimately attempting to protect the patients from suffering and maintain hope, meant that families fuelled the medicalisation of care even when death was imminent. The key findings of this chapter are summarised in the box below (Box 8-1).

Box 8-1: Key findings of chapter 8: results III

Family's central role in care provision

- Basic care giving; co-ordination of care; fighting for the system inefficiency
- Protect their vulnerable ill member- adopting decision-making roles in co-ordination of care and control communication with doctors

Family's function: a system approach

- Family function as a system, sharing roles with a split locus on decision-making and care-giving
- Dynamics changed over time with different actors adopting different roles and often changing the decision-making and trajectory
- Prior roles in the family shaped the new roles adopted. The dominant members took upon decision-making and co-ordination, whilst the more supportive adopted the care-giving roles. The illness progression and competing responsibilities in life influenced the change of dynamics

Family's decision-making of care over time

- Families' decision making was influenced by both physicians and patients. Their decisions aimed at supporting choices towards cure and preserving the relationship with their loved ones. However, the more the illness progressed, the more they shifted towards meeting patients' needs and fulfilling their wishes.

9. Results IV: Patient's involvement in care and decision-making

9.1 Introduction

This chapter presents findings related to patients' involvement in care and decision-making over time. It explores patients' experience of their illness and care. It explores the level of participation in decision-making whereas identifying ways patients communicated with different groups of health professionals and of their families.

The chapter is organised into three sections. The first section explores the different ways patients wish to relate with doctors, nurses and families. The second explores the patterns of patient involvement into their care plans, their relationship with their families and their personal journey towards dying. The third explores longitudinal aspects of their trajectories whilst identifying influential factors over time.

9.2 How do patients want to relate with their formal and informal carers?

Data suggests that patients communicated and related with the health professionals and their family carers in different ways. They wished for a doctor they could trust, a nurse who could understand them and a family who would advocate.

9.2.1 Relationship with doctors: 'I need to trust you will do the best for me, but you will also hear me out before you plan'

All patients stated that the most important element in their relationship with the doctors was trust. Regardless of their desire for more or less information, they said that they wanted to be able to rely on doctors' best advice and expertise. They also said that provision of information was not enough; they needed reassurance from their doctors that they are trying their best.

... no, it is not about me making the decisions of my treatment. I want my doctor to make the best choice. I need to trust him that he knows all best available options and makes the right one for my case. Even if he gives me the information,

I don't know what is right or wrong to do. I want him to make me feel that he knows well and that he will try his best. What to do with just information? It would rather confuse me or even scare me. (Maria, audio 9823; 3 months before death)

... of course I need the doctor to communicate with me and tell me the truth. I need to trust her that she is not playing games with me and that we do things together. But I also need her to guide me though. For example now that this treatment did not work, I do not know where I should go after. I expect her to have the knowledge and tell me what we should do next. And because I trust her, I will follow her. (Con, audio 82; 2 months before death)

Patients also mentioned that they wanted the doctors to relate to them as human beings. Sila and Giorgos complained of being treated as numbers and not as persons. Ursula and Pablo said that at times they felt that they were treated as a disease. On the other hand, Con and Fritos commented positively about two doctors who gave some time for small talk. Most patients expressed positive feelings towards the more junior doctors because they thought they were more approachable comparing to the consultants who they found hard to engage with.

... it is those professions that are dealing with human beings. Doctors must be first human beings and then doctors. (Sila, audio 359; 3 months before death)

I would like to interest them as a human being, not as a disease. ... I would like him to take his coffee here one morning and come, talk to me. Say today, before I start my day I want to have a cup of coffee with you. I will come for 10 minutes to talk about some things... (Pablo, audio10165; 3.5 months before death)

No I have not told them; because they do not care about what I want... they act all high and mighty. They come; they say their things around you and go; not even asking you how you are. (Tamara, audio10045; 25 days before death)

I am just another case for them; another bed number, which they need to fix as soon as possible, so that another number, can take the bed. I feel I am just a case for the medical staff that they just couldn't care less. (Giorgos, audio 10187; 1 month before death)

Listen, my opinion is that from a 100 of doctors here, 40 are interested in the disease itself, another 40 are interested in let's say the doctor's mask and the rest about the patient. ... What I mean about doctor's mask is their medical ego. To show off how important they are; to be treated like Gods. (Con, audio 10180; 2 months before death)

Especially around symptom management issues, patients often thought that their needs were not given priority in the hospital, as they had to adapt to hospital function instead of the hospital meeting them. All patients- especially when symptom control became vital- expressed complaints against doctors because they did not plan their care around their needs, rather than their own schedule. Those complaints became more frequent during the last two months of patients' life.

Sila came to the day care clinic today... the nurse did not want to accept her as she had not been given an appointment by her doctor. Sila was upset and told her. What do you mean why I came? It is not up to the doctor to decide when I will come for the paracentesis for my ascites. I will decide it since it has to do with the pressure in my belly. (Field notes from visiting Sila at the day care clinic; morning shift; 40 days before death)

I am not your puppet. I will come when I cannot manage my dyspnoea^{5}, not when you say. You cannot tell say when my dyspnoea is not manageable...I am not here to serve you, but you are here to serve me- the patient. (John, audio1024; 25 days before death)*

Patients seemed to request their doctors' presence and their reassurance more, as the disease progressed. The requested reassurance was not related to promise for cure necessarily; rather than doctors acknowledgement of the situation and their commitment to help and support. They explained that doctor support should include listening to the patient and taking on board the patient reported issues. They asked for help with the control of increased symptoms, but also provide support which suggested that their doctors would not abandon them. They expressed the need for the doctors to accept patients reported information in order to make relevant care plans.

I want to participate by telling you my story and you to understand me. It is not about giving me information; it is about hearing me as well so that you can understand my needs. I understand that they are very busy and they might not have time. Well, in this case, they should not accept so many patients. (Giorgos, audio 10230; 1 month before death)

How can the doctor make the right decision for me; if he does not know what is happening to me? If he does not listen about my problems; my wishes, how things change for me and take them on board, how can he make decision? (Pablo, audio10167; 2 months before death)

I cannot trust them [the doctors] anymore; I do not think they understand me. I don't think they care or realise that what really matters is to go home now. I

⁵ *Dyspnoea is a Greek word and the common term for breathlessness. For this reason, I maintained the same term in translation.

hope my children will sort this out for me; I have no energy to convince anyone.

(Sotos, in field notes, a week before death)

Closer to death, only Sila and John's data expressed requests for direct communication with the doctors, perhaps because they had established this pattern of communication all along. In John case, also, there wasn't any family member to advocate for him. Tamara and Ursula expressed feelings of being abandoned.

9.2.2 Relationship with nurses: 'Understand me and be kind to me; remind me that I am a person'

Patients did not express any views in relation to the role of nursing in the planning of their care and treatment. They did not identify any roles they would expect the nurses to have in their care, even when asked about nurses' professional roles and skills that could contribute. They instead focused on an empathetic relationship with the nurses. Patients appreciated a reciprocal, friendly relationship with the nurses, based on an everyday communication. They valued those nurses who they thought were understanding and spent time at their bedside. However, nurses who were focused more on their tasks and did not engage with patients, were perceived as cold and indifferent.

I don't care about their qualifications. To me they are worthless when they just come to give you a shot instead of taking care of you. She [a specific nurse] doesn't care; she just functions. (Pablo, audio10032; 5 months before death)

She does not care to do anything more. She just wants to get her work done and go. While the poor patient has been there in bed since the morning ... waiting to be heard, talked, felt... (Natasha, audio 358; 2 months before death)

I want to feel better and I will feel better if I can find someone to talk and understand me. I am stuck here on a bed. If that person is busy at this point, I will look for another. If everyone is too busy to talk to me, then it's over. I am screwed. (Giorgos, audio10166; 3 months before death)

Most patients mentioned the importance of a happy/smiley nurse. They were described as a good nurse, the one who smiles; is nice to them and keen to chat whilst s/he touches them compassionately. They had identified those nurses, had expressed their preference towards them and often asked if there were on duty, hoping to see them. Patients were sympathetic to the workload of those nurses and express understanding when they responded late to their requests.

They are supposed to care, right? I like it when some of them touch you. Some they do not touch you at all, they are indifferent. They just give you a quick glance, fix the drip or whatever and go. (Con; audio 10185; 2 months before death)

I want the nurse to remember my name and to be nice to me. Helena is so nice. She always smiles and says good morning. (Sila; audio 10009; 3 months before death)

Me sweet Maria is here today. I love her very much. She always speaks sweet and smiles. She is the sunshine when she enters the room. ... She must be very busy, that is why she is not coming. It is ok, I can wait, no worries. (Fritos; audio 10287; 18 days before death)

Patients discussed a wish to relate with their nurses in a reciprocal, friendly way. They wanted to be remembered with their name, and nurses to remember details for their personal life, such as family status and relevant matters they had disclosed. Simultaneously, they were interested in the nurses' lives and remembered relevant discussions of the past which they followed in their later admissions. Sila and Pablo explained that this level of intimacy made them feel like human beings and not just creatures called patients. Giorgos explained that when patients spend so much time of their life in the hospital, inevitably they want to relate to the nurses, as they become the people of their everyday life, something like the hospital family.

Eleni [nurse] has two kids as me, similar age. We talk about our kids and the schooling problems and this is nice. She makes me feel like a person again.

(Ursula, audio2012; 3 months before death)

I like Effie a lot. She always asks how I am and she waits to hear my answer. And then she remembers what I told her. And you know? I really enjoyed that I could help Rita with her essay. She made me very happy when asked for my help. You know, you help me and I help you. I can be a normal person that can contribute with my skills. It feels like an equal relationship where we both can be helpful to each other. It was one of my best weeks I have to say. (Con, audio10234; 45 days before death)

Is Helena here? How was her wedding? Is she back? I want to see pictures... well, am here for so long, I know them quite well now. Helena allows you to feel like family. She comes for advice and I feel as if somehow I am her mother. (Sila, audio1008; 40 days before death)

Des, I am a person, not just a cancer disease, a number. One of the things that help is when they remind you that you a human being who has a similar life with the rest of the people. Take for example Roula. When she comes to do her work, she asks about my children and chats normally. She always shares her news, simple normal things. She is interested in my views. She shows that she values you as a person which happens to be ill now. Sometimes, I feel like a monster, a weird creature without any hair, with all these equipment around me and all these people around who need to help me live. (Pablo, audio10166; 2 months before death)

Patients did not expect the nurses to manage their symptoms, rather than to report them to the doctors and then follow their orders. They said that doctors knew what should be done and nurses could act upon the problems, if they had a written guidance by the

doctors. Even if they did not expect nurses do deal with their problems directly, they expressed their desire for the nurses to listen to them, understand the upsetting problem and take it seriously. When they could not act upon the issue or could not find the doctors, at least they expected them to express sympathy. Also, they did not seem to expect nurses to advocate for their needs to the doctors, as this was the family's job.

All I want is for her [nurse] to understand how difficult it is for me and take it seriously. She said ok, ok, but she will not do anything about it. She just walked away. I understand they might not be able to do much about it, but at least they could say they understand and that they will try their best to help. (Sila, audio1020; 2 months before death)

Well, you cannot expect much from the poor nurses. They don't know what to do if they do not get the guidance from the doctors. And you can see that they try their best to find a doctor to help them; how much more to ask? (Fritos, audio101223; 1 month before death)

A couple of times they tried to challenge the truth through the nurses. Nurses seem to be very skilled in avoiding any answers by referring them back to the doctors, as being the knowledgeable or updated ones. They portrayed the role of following medical orders.

9.2.3 Relationship with family carers: 'Cancer is the burden, not the patient'

Data showed two important aspects of the patients' relationship with their families: the sense of unity and thus the expectation from the family to advocate for them. Patients did not separate themselves from their families, but rather saw themselves as an organic part of the family-body. At no point, did patients express a concern of becoming a burden to their family. Instead the disease was the burden which had disturbed and changed their family life.

... am thinking of what this cancer has done to us... we are always exhausted, scared , lost. We fight all the time. This is not how we used to be. I am exhausted and irritable with the treatment; my wife is exhausted and has no patience. Hope he [cancer] will not break us. (Giorgos, audio 10230; 4 months before death)

I am really worried about Soula [his wife]. She needs to lie down but now I need her to stay next to me [during the nights]. I cannot be by myself. What can we do; we need to help each other. But really now, I just need her here. She will rest later. (Fritos; 10251; 20 days before death)

The pattern of that the patient makes decisions with the family followed from the belief that the family works together united against the problem of the illness. Patients did not seek independent advice and did not express the need of making independent decisions from their families. Instead they expected the families' involvement and at times they requested their families to make decisions of care.

I want my family to be next to me; I want my family to help with the right decisions; I am not feeling well and I cannot sometimes understand what they doctors say; while my parents run behind the doctors and gets the updates. I am happy for them to take the lead; who else would fight for my best [interest]? (Natasha; 10013; 2 months before death)

Jella has become better than a doctor. She remembers everything, she even corrects them. It has all become too complicated for me now, I cannot follow this up. I tell Jella what I want and then she goes and discuss with the doctors. She knows me, what I want. Jella can get the best available for me; I know this. Didn't you see how she brought the orthopaedics to see me, while my doctors here said that they could not find them... (Pablo 10176; 5 months before death)

Similarly, patients seem to adapt their wishes in order to accommodate the family wishes. When asked if they had compromised, they felt that this was natural, as family deals together with the issues and all members try to support each other.

Yes, I have not changed my mind of dying at home but Iris would not manage. It would be better for her, if we were here around people to help. She would be scared. No I do not feel sad or suppressed. I am really happy if I can support Iris in this. I want to be her man. This is really more important; we need to make decisions that both of us can cope with; it is not just about me (Giorgos 10254; 2 weeks before death)

During the last days of life, patients seem to adopt the role of supporting the family accepting their imminent death and most of the times took the lead with the dying preparation. Almost all patients, regardless of their prior style of involvement in decision-making, lead the preparation and made their families to follow. Patients wished for their families not only to be present, but participate and help them achieve their dying preparation. They asked for their favourite food, they asked them to find their favourite clothes; they sang together; they held hands. Dying was observed to be not a lonely process, but a family experience.

9.3 Patients' patterns of involvement in the decision-making

Three patterns of patient-involvement were identified over time: 1) direct communication with the health professionals (actively seeking for information/participation in decision-making); 2) involvement through families (requesting their family to advocate) and; 3) relying on the doctors (trusting doctors as knowing best). It should be mentioned that these patterns were not mutually exclusive and there was occasionally overlap between those patterns. For example, some patients chose not to be involved directly with decisions of care, but actively involved with maintaining their role within the family. In other occasion, patients who relied on their doctors for the care decisions, near

the end of life wished to communicate directly and actively sought participation in decisions, whilst trying to assure the space and time for their dying preparation.

Patients showed three areas which they wished to be involved and within which the above patterns were observed: 1) care plans and treatment options; 2) family relationships and; 3) last preparations of dying.

9.3.1 Care plans and treatment options

In relation to decisions about care plans and treatment options, patients were directly and indirectly involved in decision-making throughout the course of their illness. For some patients, mostly families and doctors made the decisions of care over time.

A shared decision-making

The decisions related to care and treatment choices followed mostly an indirect pattern, when the patients themselves wished to be involved. In most of the cases, patients seek information through their families and discussed their wishes with them. I often observed patients requesting their family members to look for doctors and pass their concerns about care plans, receive updates and even report symptoms. The common pattern was that the family would advocate for the patients' wishes and requests to the health professionals and then come back to discuss the outcomes with the patients. They would then negotiate the next steps and consequently the families would revisit the doctors. I only came across with one situation of a patient wishing to make a complete autonomous decision, without requesting the support of a loved one; and that Giorgos when his marriage went through a crisis. Patients seemed to need help to make their decisions. In all occasions they discussed their concerns and wishes with their families and most often patients perceived that the decision was made by both of them.

Come on my daughter; go and find Dr B, please. You need to ask him what the test results were today. Is the treatment working or not? Please, go to find him

and then come back to tell me. We need to see what we will do... (Sotos, speaking to his daughter, audio 10098; 4 weeks before death)

Advocacy

Patients explained that they appreciated the support of their families in dealing with the all the health issues, as often felt very tired to follow up updates and changes/ complications. Also, they reported that often they felt weak in fighting their corner but also it was very hard to find the busy doctors and discuss with them; thus, the families relieved them from such a burden. No patient reported any concern that their family would not advocate for their best interest. Family's involvement was considered a proof of love and advocacy by the patient, and that was another reason for preferring this pattern of involvement.

A patient like me must have multiple resistances, endurance. I for example, need to have the strength to mobilise myself, to eat, to tolerate pain, think of my jobs I left behind. It is so complicated and so many things at the same time. I would not be able to manage without Jella. At least she runs to the doctors and co-ordinates the things here and I can focus to the constant adaptation. ... Now I need to focus on recovering from the fracture, let Jella take care of the cancer treatment. (Pablo, audio 10170; 2 months before death)

Management of conflicts between families and patients

Neither doctors nor families discussed the prognosis of illness with the patients. Hence, no conflict was recorded with regards to treatments whilst both patients were still focus on the fighting. In one case, conflict with regards to treatment options was observed between the couple who was faced with problems in their marriage.

Iris and Giorgos have been fighting all week. Giorgos said no to the scan, because Iris suggested it. They seem to compete with each other who is right and who is

wrong. It seems that the problems of their relationship are projected to the decisions for care plans. (Reflective diary, on Giorgos case; 5 months before death)

There were occasions where families did not support the patient's wishes, rather than their own preferences or the medical opinion. That was evident when it came to the decision of stopping treatment and the wish to die at home. For example in the case of Sila, the family's preference was to continue treatment until the end, despite the wish of doctors to support Sila's preference of ending treatment. However, when families openly disagreed and colluded with doctors' opinion, patients assumed that families had not been given the option by the doctors or that actually they could not understand them.

Jella does not get it. I want to go home; there is no point of staying longer here. But on the other hand, it is not her fault. Dr Bonus does not let us go. He said we should try x medication, what can she say? Thank you for trying but I don't want your help anymore? (Pablo' audio10220; 35 days before death)

In a few occasions when patients wished to stop treatment and return home, they acknowledged that families were not ready to give up. For this reason, the patients chose to support their families in their wishes, as fostering the relationship was more important.

Giorgos stopped asking to go home the last two days he was in hospital. He said he was fine and the only thing he asked was his favourite coffee. When I asked him, he said to me that Iris was panicking at home every time he became breathless so he said it would be better for her if they stayed in the hospital. He said that his main concern was to make things as best as possible for Iris. The night he died, he sent her home to rest and said he was feeling much better. (Reflective diary, Giorgos; one day after his death)

9.3.2 Family relationships

Although patients seem to have a more passive role in the decision-making for their treatment and care, they sustained an active role within their families. Maintaining their roles in the family and be actively involved seemed to be the focus at almost all times. As one patient explained, being ill did not mean that they should stop living. Indeed, most of the recorded patients' decisions were related to their relationships with their loved ones.

The patients who were parents, allowed their children and others to make decisions for their treatment and take the responsibility of their care, but they actively worked on their parenting role. They always wanted to be informed about what is happening in the family and wanted to give their advice while expecting to be followed. Pablo obeyed his wife when it came to food or washing up, but insisted in getting informed about their children progress in the university and also maintained controlled of their finances. Even when being poorly and not able to follow not following up the pain management or the specific treatment decided for him, he remained active in supporting his daughter with a personal issue and kept calling his son to make sure he is following his exams.

Today Pablo seems not willing to communicate. Doctors passed by during their round and he did ask any questions- very unusual for him. He keeps his eyes closed for most of the time and accepts Jella [his wife] to do anything she wants with him. He says he is in pain and has no energy... (Field notes, Pablo; morning shift; 20 days before death)

[Two hours later].... Pablo's daughter came and he suddenly woke up. He observed her for a few minutes and asked her how things were with her boyfriend. He asked details about her work and gave her advice. He guided her on how to deal with her boss and offered some words of wisdom about love. He did not seem exhausted as before. (Field notes, Pablo; afternoon shift; 20 days before death)

Patients seemed to focus more on the relationship with their loved ones, and this is perhaps one of the reasons they supported their families' wishes. There had been occasions where patients decided to follow their family wish, not necessarily by compromising their own preferences, but because they prioritised their loved ones. As they explained to me, it was not an action based on guilt for overburdening their family, but an action of caring for them.

... Especially because I am going, this becomes the most important thing. I want to make my relationship as happy as possible and leave my wife with loving memories. This will be that last gift I will offer her. (Giorgos, audio 102333)

Becoming a burden to the family was not manifested as a concern by the Greek patients. Patients were concerned about their families, but it appears that they saw the problem as a problem for all. Con explained to me once:

I know my mum is very tired; well the whole family has changed after I got ill. Our life has changed; cancer has messed up with our life and we all try to manage. But then, isn't it how it is always with life problems? We stick together and we fight it. I would do the same for them as well (Con, audio 1292; 3 months before death)

Nonetheless, when the family was dysfunctional, such concerns were raised. In Giorgos' case, when his marriage was challenged, thoughts of becoming a burden emerged. During that period Giorgos expressed feelings of guilt and worries of becoming a burden to his wife. When though, their relationship improved, such concerns were not again discussed.

You know, sometimes she makes me feel she stays with me out of duty and that she feels she should stay now I am ill. Not because she wants to. I don't want to think she might feel trapped with me; if it is so, I want her to go. (Giorgos, audio 101304; 5 months before death)

9.3.3 Preparing for the journey: place for spending the last moments of life (place of death)

During the last days (one week to a few days before death), patients actively expressed preferences in relation to preparing for dying and made clear requests in relation to the place of care and death (Table 9-1). Eight out of the thirteen cases presented with dying rituals, which the family seemed to recognise and support. In a few cases where they did not recognise them, they felt guilty afterwards as they thought they had failed to fulfil the patients' last wishes. Ten out of the fourteen patients wished to go home before they died. Two of them experienced uncontrolled pain and dyspnoea and asked to stay in the hospital. Two patients did not consider it important the place where they would die, as long as they could prepare their soul for the journey; both of them were active Christians. One patient who had no family next to him, he wanted to stay in the hospital because he did not want to be alone. One patient who previously expressed a wish to go home, in the end, decided that it would be better to stay in the hospital, as he felt that his wife would not be able to cope with his dying at home.

Table 9-1: Preferred and actual place of death, and dying rituals

Patient	Preference for place of care at the end of life	Preference for place of death	Actual place of death	Dying rituals
Con	hospital	Indifferent (preparation is important)	hospital	Invited the priest, received the holy communion.
Natasha	Home	Home	Hospital	None.
Maria	Home	Home (be with her child)	Hospital	None.
Giorgos	Home at first, then hospital	Home	Hospital	Asked his special coffee and asked to be washed and shaved some hours before.
Pablo	Home	Home (dignified death)	Hospital	Sedated.
Ursula	Home	Home (good death)	Hospital	Asked to look over the sea.

9. Results IV: Patient's involvement in care and decision-making

Kula	Home	Home (among the family)	Hospital	Unconscious.
John	Hospital	Hospital (not to be alone)	Hospital	Asked to be cleaned.
Tamara	Home	Home (with her grandchildren- but indifferent near the end)	Hospital	Invited the family for the farewells, requested specific clothes and choose to dress for the journey, she gave blessings to her children.
Sila	home	Indifferent	Hospital	Asked for her favourite ice-cream, jasmine and the priest to give her the holy communion.
Mina	home	Home	Hospital	None.
Sotos	Home	Home (dying next to ancestors)	Hospital	Asked to be taken in front of the sun, sung farewell songs, blessing to his family.
Fritos	Home	Home	Home	Asked for his special food, to be taken in his backyard overlooking the lemon tree, against the sun, called for the priest and received the holy communion.

Being at home near the end of life seemed to be important to patients for different reasons. For some patients it was part of the farewell process; they needed to say goodbye to their homes and gardens, their neighbours and friends. For others it was the pleasure of enjoying the last moments of life in the best place to be. For another two, it was the importance of dying where their ancestors had died before and being buried with previous family members. It was the sense of being united with the diseased family members who would come to escort them to their journey of afterlife. However, only one patient managed to leave and die at home, a day before his death. The lack of home care services, the uncontrolled symptoms; the doctors' reluctance to allow them to go and the families' concerns that they would not manage alone at home were some of the reasons that influenced the final decision of keeping the patient in the hospital.

I want to go home. There, I will have the entire neighbourhood- friends to help me and my wife. Here we are just the two of us, having our friends for a visit whenever they can. (Fritos, audio10247)

I want to die back in my home; there my partner will help me to do the things I like; here I am alone. (Ursula, audio 1243)

I prefer to be here when it happens. I don't want to die alone, unsupported like the deserted dog in the vine [Greek idiom]' (John, audio 10120)

Nonetheless, patients lead the practice of preparing for dying and encouraged their families to follow the dying rituals they performed. Older patients who came from rural areas, had clear ideas of the rituals to be performed which are embedded to both the ancient Greek culture and the Greek orthodox religion (see Chapter 2). On the other hand, younger patients from the big cities seemed not to have a particular preparation process.

A clear example is Sotos who was coming from the mountainous area of Greece and insisted in performing a particular ritual, coming from the ancient Greek tradition.

Sotos asked to be taken somewhere to face the sun and sing a few songs. The whole family hugged and kissed each other. They took him with a wheelchair in front of the window to face the sun; he barely sung two songs. One was referring to a proud eagle which was dying up in the mountains and the other one to somebody who was leaving his homeland migrating far away. (Reflective diary, Sotos; 10 hours before death)

Sila, Giorgos, Con, Tamara, Fritos and Sotos requested to taste their favourite food or drink some hours before death.

Sila refused to eat food for the past two days. But today she asked her niece to get her the x ice-cream. Her niece was surprised but she went to get it. Sila also

asked some Jasmine from her garden. She said she wanted to take with her, her favourite taste and smell for the journey. Her family started crying. Sila told them she loved them. (Field notes, Sila; 2 hours before death)

Giorgos requested was his favourite coffee, a habit he had quit from for several months. 'I want a fredochino; I longed for a fredochino' he said during that evening before his death. His wife surprised with his request asked him if he had gone mad. It was already quite late, the lights in the room had been switched off and only the little lights on top of the beds lightened the room. A few of other patients in the room were asleep and it was relatively quiet. Giorgos repeated the same request, but Irene found it unreasonable. 'Are you mad? Do you know what time is it? And anyway, it will not do any good to you; no I am not going to buy any. (Field notes, Giorgos; some hours before death)

Patients, who were more religious, seemed to focus more on the preparation rather than the actual place of death. Sila and Con who were quite religious, suggested that the place of death was not important, but preparing for the afterlife was vital. And that, because they believed that they would meet with their loved ones in heaven one day; purifying their soul was vital in order to meet this target. They requested to see a priest the day before death in order to confess and receive support from the priest. They requested to receive the Holy Communion with the hope of getting God's strength to face the impending death.

Why they make it such a big deal? It does not matter where your body is when you go. The soul will find its way up to God. The important thing is for the soul to be ready to face the Lord. (Sila, audio 1912; 10 days before death)

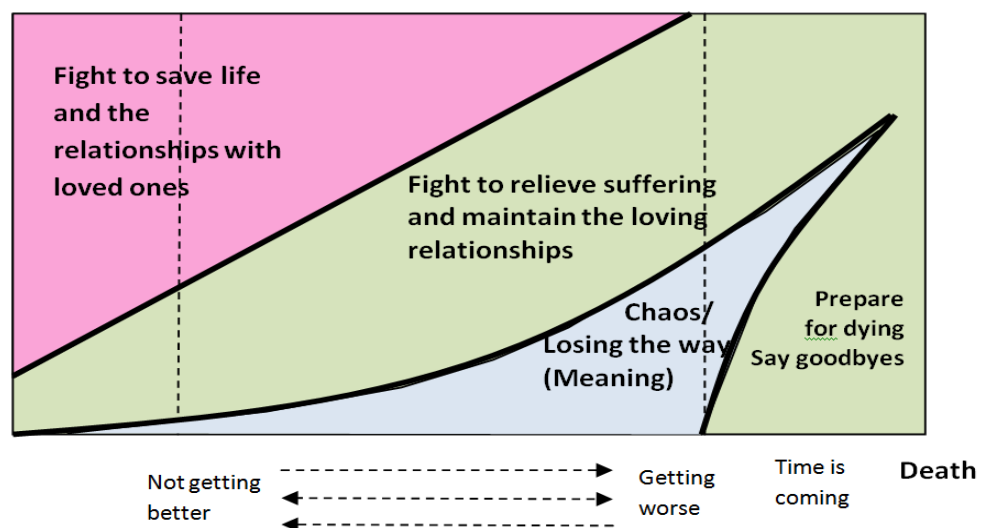
Con, insisted for father X to come to see him tonight. He asked us to leave the room so that he confesses and receives the Holy Communion. When he left, he said to me: 'I was worried that I would not manage to prepare. (Field notes, Con, evening shift; the night before death)

All patients asked for their family to be around, held hands and said goodbyes. Tamara and Sotos made the farewell quite formal when asked to talk to their children. First, they requested to see them one by one so that they can give personal advice and blessing to each one of them; in the end they asked all the family to sit together in order to give the final and overall guidelines of how the family should move on and lived their lives in the future. All were aware of the meaning of those discussions and as some family members said later on, they found this process very moving but also it gave them the space to say goodbyes, declare their love and finish whatever was still on hold. They also said that if the patients had not taken the liberty to do so, they would not be able to initiate such a thing themselves. They felt that their parent lead the way out.

9.4. The longitudinal experience

The stage of illness proved to influence the degree of patient wish to participate in the care plans, but also the matters the patients wished to get involved at. At different stages, patients seemed to focus at different issues and therefore at different decisions. At a certain time point, often there were many decisions to be made, which might require different focus. Patients did not choose to engage with all of them at all times. Instead, they seemed to choose where to focus and every time the focus might change (Figure 9-1).

Figure 9-1: Patients' focus of decision-making over time



Also, when illness circumstances changed, the importance of a specific preference occasionally changed. For example place of death was not very important for Giorgos anymore, as supporting his wife had become an imperative. Often there were competing preferences, and in this situation, prioritisation of them influenced the outcome. Indeed most of the times there was not just a single decision to be made. It can be multifaceted.

For example, when patients believed that their disease was curable, they were prepared to follow the doctors' suggestions despite the side effects or the sacrifices they faced in their quality of life. At that point, both families and patients trusted completely their doctors' decisions of care and wished to follow whatever treatment option was given. However, when patients felt that there were not improving, preferences of quality of life and time with the family seemed to gain importance. At that stage they started negotiating more time at home, less aggressive treatment in order to reduce side effects, and thus have more 'normal' time with their loved ones.

When patients realised that they would not get better and instead worse, then they seemed to focus more on symptom control and the family relationships. Despite the fact that they still would prefer options of cure, they felt that perhaps this would not happen and thus the focus changed. Usually it was the patients who pushed towards this direction and made families to follow. Families seemed to maintain hopes for longer. Pablo explained that his wife could not understand that his body was dissenting him and instead accused him for really not wishing to fight any longer. When he started expressing a wish to go back to Crete and spend quality time with his wife and children, his wife tried to convince him out of it and redirect him to active treatment.

Decisions over alleviating uncontrolled symptoms often took priority for the patients and changed arranged plans. Symptoms of pain and breathlessness seemed to trouble patients the most. When they remained uncontrolled, patients were observed to change their plans. While Pablo agreed to opt out from the operation over his left hip fracture, he fought to

change that decision because he found the pain unbearable. Despite the opposition of his doctors, he signed to take the full responsibility even with the risk of dying, in order to reduce his suffering. On the other hand, when symptoms were not controlled effectively, other patients chose to focus on different matters, perhaps with the hope of a distraction. In that situation, they seemed not to be actively involved in their care and rather seem passive. However, they became more active with the family matters and wished to be involved in the relevant decision-making. Tamara seemed to have focused completely to her family five days before her death. She stopped asking about the treatment plans, and kept saying to her daughters that they should do what they think is best. Yet, she started asking a lot more about her grandchild and the marriage plans of her daughter, while chasing up her son to finish his studies.

Another aspect which changed over time seemed to be the locus of control. Whilst disease progressed, the locus of control seemed to gradually change from the outside to the inside. This probably affected their decision-making focus. Sotos first decided to stop fighting and communicated with the nurse. Hence there was no more need to be involved in care or requesting for future plans. Then he focused only to his family. When he decided that it was time for him to go, he called for his family, said his farewells, and performed the dying rituals with their help. After that, he had no wish to communicate. He prepared himself to go and closed up to himself. After he performed his sun ritual he remained silent in bed. He looked as if he withdrew to himself. His family interpreted his withdrawal as preparation of departure and felt they had to respect his decision. As a consequence they stopped moving him and trying to make him engage into discussions. The locus of control seemed to have turned inside. At all points he probably had control of a certain decision, but the focus was much different.

Almost all patients seemed to develop awareness of dying, despite the fact that their prognosis was not disclosed to them. Fritos who was not aware of even his diagnosis, he seemed to realise his dying. The awareness of dying seemed to trigger a change of attitude

in patients. No matter if they had been dominant or not, they seemed to want to take the responsibility of their last moments. Instead of negotiating with their families, they seemed to have taken the lead and asked their families to follow. Sila told me a few days before her death that those moments were a very personal journey that only by yourself could walk'. Families were there to witness and escort until the point of death. This change of attitude seemed to trouble doctors who seem not always able to realise and either insisted on what their plan was or completely withdrew. On the other hand, some of the experienced nurses found those moments empowering.

When patients realised that dying was near, most of them opted for going home, spend time with the family and say the farewell. The personal and family attitudes towards dying and death, alongside with the tradition and religious beliefs; the presence of uncontrolled symptoms directed choices and decisions. The following table presents the individual factors who lead to decision of most all patients to die in the hospital (Table 9-2).

Table 9-2: Main actors in deciding place of death and influential factors

Patient [place of death]	Main actors in decision- making	Factors influencing decisions
Con [hospital]	Parents-doctors	Symptom- physical management Anxiety of the family of managing body
Natasha [hospital]	Parents-doctors	Disease complications
Maria [district hospital]	Family	Anxiety of handling end stage, local beliefs
Giorgos [hospital]	Giorgos-family-doctors	Symptom management, Giorgos anxiety of breathlessness Spouse's fear of family criticism
Pablo [hospital]	Spouse-doctors	Symptom management Anxiety of the family with end stage
Ursula [district hospital]	Friend-doctors	Symptom management Guilt of carers

Kula [hospital]	Family-doctors	Physical management Patients difficulty of accepting dying
John [hospital]	Doctors	Symptom management Being alone
Tamara [hospital]	Family-doctors	Symptom management Children's fear of death
Sila [hospital]	Family-doctors	Symptom management Family anxiety
Mina [hospital]	Family-doctors	Symptom management Exhaustion of the carer
Sotos[hospital]	Doctors	Symptom management Fears of doctors of sending him away without any home care
Fritos [home]	Fritos-spouse-doctor	Respect of his choice

9.5 Exemplar cases

Two cases are briefly presented bellow, as illustrative examples of the longitudinal experience of dying and care.

9.5.1 Fritos' case

Fritos was a man at the age of 75, living with his wife. He died two years after his initial diagnosis with liver cancer and lung metastases. In this study, he was followed for two months prior his death, until his death. He was a jewellery maker and owned a shop which he recently handed it to his wife's son. His wife seemed to have the dominant role in their relationship and often suggested that Fritos had been dependant on her for all of his life. Fritos often told me that he would have not made it in life if he did not have his lovely wife. They share a very close and intimate relationship. They lived in a suburban are outside of Athens, where many Greek refugees from Konstantinoupolis (Istanbul) had settled down during the 1950s.

Fritos had expressed his preference in having his wife discussing with the doctors and then him to discuss it with her. He said he found difficult to negotiate with doctors, especially when he had to say that he could not manage with what was asked from him. Also, he found that they spoke very quickly so he was missing things and also often could not understand the words they used.

Four weeks before his death, he is told by his wife that he had a rupture, and that was the reason he had ascites. He felt he could then overcome the crisis and suggested his wife to take intervals of rest at home. He says he is positive that he will go home soon and he likes chatting with other patients and their relatives.

During the third week before his death, two patients massively bleed in the room and one died while being breathless. He then questions why he is in a hospital that everyone dies, and is being told that because their doctor could not see them anywhere else. He is starting developing renal failure and develops oedema. His mood seems to change and he spends hours looking outside of the window. He does not wish to engage to discussions and his face looks worried. He becomes abrupt and refuses to let his wife to go away.

During the second week before death, his breathlessness is not controlled and keeps asks help to get his breath back. He constantly has the oxygen mask on and cannot lie in bed. He wants to follow all treatment religiously, hoping to see some improvement but soon he realises that he only gets worse.

During the last five days prior death, he says that he had a dream where all of his family members who were already dead visited him and spent the whole night with him. His breathlessness and oedema is getting worse. Two days before death he said to his wife that he does not want to die in the hospital and requests to go home. They sent him in an ambulance where he settles peacefully for one day. He invites all neighbours and friends to say goodbye. He requests to sit outside in his garden to see his lemon trees. He eats his favourite food. The next day he requests for the priest and receives the Holy Communion.

While the priest is leaving the room, he makes his cross, closes his eyes and dies peacefully.

9.5.2 John's case

John, a patient with lung cancer at the age of 60, had no family; He was divorced and had no children. A neighbour friend, who was visiting him sometimes, told me that John had pushed away all of his people due to his difficult character. John did not have good relationship with the health professionals. Doctors said he was not obeying to treatment and he was rude while nurses thought he had bad manners and not respectful behaviour towards them or other patients and families. John on the other hand, expressed his feelings of being treated without dignity, like a child who just had to obey and that he had to fight for his right to be informed and make decisions for himself. Since John had no family to advocate, he had to work with the doctors directly: informed about his condition and treatment options. He also needed to look after himself both at home and hospital, as he had no informal care (e.g. help with basic needs- being cleaned, help with food but also deal with the bureaucracy of the health insurance, authentication of his medicines). As he got worse, the need of having somebody at home next to him became more urgent. John negotiated his support by seeking help from the social service of the hospital, engaging a neighbour and hiring a private health assistant for when admitted to hospital. The social service of the hospital was involved with the matters related to bureaucracy of the system and the hospital, during his admission times.

John 3 months before death he worked on maintaining control of his life and care. He fought for more treatment and demanded time from the doctors. He refused to be treated in wards with poor facilities and tried to manage his condition at home when he was not having chemotherapy. He paid his neighbour to perform all external tasks for him (e.g. shopping, going to the pharmacy). He also paid a private health assistant to look after him in the hospital- very focused on staying clean and having good food which he orders from outside the hospital. He was discussed as the difficult patient who they wanted him out as

soon as possible and he argued that he was treating the system with the same ruthlessness as the system treated him.

A month before death he suffered uncontrolled breathlessness and fatigue. He also had an episode of chest infection which needed treatment in the hospital. He had developed cachexia and had several episodes of breakthrough breathlessness. He burgeoned with his neighbour to move in with him. The neighbour spent more time with him, visiting him every day. He tried to hire the same private health assistant 24/7 so that he would not be alone, as he could not sustain himself. She did not accept the work but she responded to the emergency calls. She was called in a number of breakthrough breathlessness episodes which she dealt with by injecting him steroids.

Two weeks before death, he visited hospital himself and asked to be admitted. He could not eat and the pain and breathlessness were uncontrolled. At first the doctors refused, but then accepted him as they felt he had not enough resources to deal with his breathlessness and pain at home. His requests were not anymore around treatment, but only around symptom control.

Three days before death, he had high fever and sweated a lot. He was also in a lot of pain. He had episodes of delirium, particularly when high fevered. The doctors decided on IV morphine, which started sedating him. Diarrhoea seemed to trouble him a lot, as he was concerned with staying clean and nurses did not respond promptly to his request to be cleaned. He said he wanted to have control of what was happening, so refused the IV morphine and IV hydration. Being hydrated, meant he would pee more often, which he could not control well and thus needed more attention with getting cleaned. As he could not have it, he refused hydration, as being cleaned was more important. He only accepted medication would stop the diarrhoea and moderate pain management. *'I will keep the little injections they do in the arm for the pain but only this; I don't want hydration or anything else; am fine. I need to have control of the process'* (audio 10083, 3 days prior death).

Two days before his death, he called his neighbour friend in the hospital, in order to arrange the final issues of preparation. He passed on to him his last savings to thank him for his support and asked me to find the clothes he wanted for the funeral.

A day before his death, he accepted the IV online. He said to me *'At this point I would accept anything, even you to torture me. Do whatever you want, I am dying anyway'* (audio, 10099, 14 hours prior death). After he recovered from a delirium episode I told him I was a bit scared and I asked if he was in pain or if there was something we could he replied *'Don't we expect it now, why scared... No, I am ok, nothing matters now?'* (audio100110, 6 hours prior death) The only thing he asked me was to stay next to him, and If possible, to help him remain clean. When I asked him how he felt, he said that despite him being agnostic all of his life, he now believed that there was something out there, a Power or God, and that his existence would not end here. He said he was in peace and ready to move on. Tears came out of his eyes (Field notes for John, evening shift, hours prior death). Some hours before his death, he asked me if I would consider him an attractive and charming man. He died while waiting for the male nurse to come and clean him after diarrhoea.

9.6 Summary

This chapter has focused on the patients' involvement in their own care, exploring their unique journey and experience towards the end of life. Patients described the characteristics they desired in their doctors, nurses and families. These wishes reflect the roles that these different groups play. An overarching theme was to be treated with respect, as a human being, and not as number or a disease.

Patients wanted to be involved in 3 areas 1) care plans and treatment options, 2) family relationships and 3) last preparations of dying. The family members remained the negotiators of care, patients clearly sought information indirectly through their families, reinforcing the trust and the unification of families.

Preparation for death occurred during the last few days, with patients actively expressing preferences in relation to the place of care and death. When faced with imminent death, patients adopted the role of supporting the family, and took the lead with dying preparation. This included requesting favourite food, clothes and singing.

Although 10 out of the 14 patients requested to go home before they died, only one actually died at home. The reasons for this are multi-factorial, uncontrolled symptoms, a lack of home care services, doctor's resistance to going home and families concern that they would not manage, were some of the barriers to achieving patient's wishes. The key findings of this chapter are presented in the box below (Box 9-1).

Box 9-1: Key findings of chapter 9: results IV

Health care culture

- Care was focused on cancer treatment; no holistic care: focused on cure and prolonging life until the late stages of disease; no space for transition to palliative phase.
- lack of co-ordination of services and lack of psycho-social support
- Relationships giving emphasis on the system; power balance and hierarchy determined by the doctors- no teamwork

Doctors' attitudes and role

- Decision making was doctor centred at the treatment level
- Doctors persisted in fighting against cancer and death. When patient did not respond to treatment, they intensified their efforts.
- Non acceptance of death; no concept of good death
- Doctors perceived families as a supporter in convincing patients but also a burden

Nurses' attitudes and role

- Good death is the sudden death without suffering; not a cancer death
- Nurses focused on task-based care.
- Nurses avoided connecting with patients, due to the burden of dying often with uncontrolled symptoms. Instead they adopted a role in supporting families to deal with dying phase.
- Nurses perceived families as part of the team but also as a barrier.

10. Discussion

10.1 Summary of main findings

This study presents in-depth evidence about the experiences of illness and care of patients with advanced cancer and their families, over time until death. It is also the first ethnographic study of advanced cancer in Greece. Grounded on social constructionism (Giddens 1984), the study focused on the interaction of the patients with all those involved in their care during their last months of life. Given that there is very little longitudinal work in cancer care and palliative care research (Steinhauser 2005), the study makes a significant contribution towards understanding how people interact and negotiate choices about end-of-life care, whilst exploring the dynamics within the family and the health care context.

The study followed intensively thirteen patients with advanced cancer for a period of between three weeks to six months each, as they came into contact with an oncology setting and other health care services in Athens. Patients, 34 family members, and 45 health professionals involved in their care were interviewed (total 75 hours) and observed (total 830 hours).

The findings showed that the care provided and the everyday life of patients and their families were more than objective independent realities. Instead, they developed over time expressed through the illness itself, the context of care, the patients and families' experience of illness and care; and the dynamics of all those involved. Indeed, the different perceptions of how the illness progressed, the attitudes of what constituted appropriate care, the values in relation to good death, the readiness to accept and engage with a dying process, the perceptions of different roles, such as of the decision-maker; the ways families functioned and patients and families and health professionals beliefs shaped the everyday life of those participants. Accordingly, the care evolved over time whilst being influenced

by the views, preferences, wishes and decisions of all participants. Although these aspects shaped the construction of care and experience, it should be noted that at different time points, different participants were most influential, depending on the current power dynamics and the specific decisions to be made.

The findings revealed four main areas related the trajectories of illness and care for patients with advanced cancer in Greece: a) culture and nature of care delivered to advanced cancer patients; b) decision-making of care and its contributing actors; c) family's function as carers to their ill member; and d) experience trajectories over time (Table 10-1).

Table 10-1: Main findings of the study

Culture and nature of care	<ul style="list-style-type: none"> • Care provision gave emphasis on the system; hierarchical with power balance challenges mostly related to cancer treatment; Focus to cure and prolonging life, no space for transition to palliative phase • Views on good death: Doctors- there is no good death; cancer is the beast and both cancer and death are the enemies. Nurses: good death is not suffering; sudden death. Cancer death and dying cannot be good, due to slow deterioration and often uncontrolled symptoms • Doctors and nurses perceived families as both a supporter and a barrier
Decision-making of care and its contributing actors over time	<ul style="list-style-type: none"> • Decision making of treatment was primarily doctor centred • Family led decisions over provision of basic care and co-ordination • Patients initiated the dying phase and preparation rituals of death
Family function	<ul style="list-style-type: none"> • Family operated as a system; organised themselves around two main locus of decision-making and care-giving • Dynamics changed overtime and four patterns of function identified, impacting on the patient trajectories • Prior roles in the family (dominant members often assuming decision-making), the illness progression, and the balancing act between doctors and patients shaped their focus and decisions over time
Trajectory of experience, priorities over time	<ul style="list-style-type: none"> • The experience trajectories were recorded as the mindset of priorities over time. • Families 'priorities balanced between doctors and patients' wishes. Over time, their priorities shifted from supporting choices towards cure and preserving the relationship with their loved ones, to meeting patients'

	<p>needs and wishes.</p> <ul style="list-style-type: none"> • Patients' wishes to relieve their symptom burden increased with the condition's deterioration. Their focus shifted from securing their life to family stability and dying preparation near the end. • All patients developed awareness of dying. Accepting dying was an active work of securing time and space for the dying preparation whilst they communicated it with certain rituals
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This study showed that the care provided to the participant patients, who all died from cancer, was focused on cure and prolonging life until the late stages of the disease, allowing little opportunity for the transition to a palliative phase. The decision-making about care was mainly doctor and family centred. Doctors were most influential on the treatment plans in most of the patient trajectories; families dominated the co-ordination of care and dealing with the everyday practicalities; the patients led the process of dying and pressed their families to advocate for ending aggressive treatment, even in the last days of life.

Both the observational and interview data showed that families have a central role in the provision of care. They employed a systemic approach in their function as protecting carers of their vulnerable ill member, sharing roles with a split locus on decision-making, and care provision. The study also found that the focus of family decision-making changed over time from cure to care, whilst the symptom burden increased and the illness progressed. Four patterns of family function were revealed: a) the main carer leads the decision making until the end; b) the main decision maker being replaced by another family member who often changed decision making and consequently the trajectory; c) the patient keeps the leading role of decision making and directs the family; d) the decision maker remains the same until the end, but other members of the extended family take charge of the care-giving roles at different time points. The way family members related to each other, influenced the way decisions are made. Sociograms helped in revealing, unpacking the system of operation, as dominant members of the family got the decision making lead roles.

Patients' shifted their focus over time which formed different preferences and decisions whilst walking through the different stages of the illness trajectory. The more the disease progressed, the more the patients focused on maintaining and for some also developing their role within the family. During the last two weeks of life, they gave priority in preparing for dying and their death. Indeed, when patients realised that they would not get better, rather than worse, preferences over quality of life and time spent with the family gained more weight; less treatment but more symptom control; less time in the hospital but more time with their families. Almost all patients developed awareness of impending death, despite their prognosis not having been disclosed to them. The awareness of dying seemed to trigger a change in attitude where patients gained control and actively led their families towards death, by securing space and time for the dying rituals.

10.2 Methodological quality

The issue of quality in qualitative research has troubled social scientists and researchers for at least a quarter of a century. The introduction and expansion of qualitative methods in health services research has necessitated scrutiny of qualitative research. Users and funders of research had an important role in establishing guidelines for judging its quality (CASP 2010; NICE 2007). A debate of distinct positions between establishing any criteria for assessing the quality or adopting criteria used for quantitative research, or developing separate criteria is still ongoing (Blaxter 1996; Rolfe 2006, Mays & Pope 2008). Initially a dichotomy between epistemologies and paradigms was discussed; placing quantitative research under positivism/realism and qualitative research under interpretivism-antirealism/idealism and therefore suggesting that qualitative research could not be assessed with the same criteria as quantitative research - validity, generalizability and reliability (Polit & Hungler 1995; Powers & Knapp 1990). The advocates of antirealism supported that qualitative research does not accept a single, unequivocal reality or truth which is entirely independent of the researcher and the research process. Instead, they

supported the view of multiple perspectives of the world that are created and constructed in the research process. They offered different criteria for rigour, such as trustworthiness, reflexivity, transferability and authenticity (Janesick 2000; Schwandt 2001; Tobin and Begley 2004). Extreme relativists and idealists- taking a step further- argued that assessing validity is not possible at all; as they believe that our perceptions of the world can be only subjective and that the world fundamentally exists in our minds (Murphy et al 1998).

The dichotomy between qualitative and quantitative research approach, appeared to simplify the differences as it viewed the methodological distinction (qual/ quant) as identical to epistemological distinction (positivist/ interpretivist) (Holloway & Wheeler 1996; Morse & Field 1996). Indeed, qualitative research is not homogenous, and different views do exist within the paradigm, with some arguing in favour of a reality out there to be studied, captured and understood, adopting a more realist approach (Denzin & Lincoln 2005). Also, approaches such as critical theory and feminism would not fit within this dualism (Sarantakos 1993). Rolfe (2007) said that neither the distinction between qualitative/ quantitative paradigms nor the coherence and unity of the methodologies within the qualitative paradigm, is as clear cut as we have been led to believe. Hence instead of arguing which approach to validity we should take, we should recognize that qualitative research is neither completely distinctive nor separate from quantitative research studies. The view of employing exclusively either epistemic criteria of validity (about the research itself) or aesthetic criteria (the way research is written and presented) does not cover the breadth and scope of the qualitative paradigm.

The debate in relation to quality of the qualitative research has not left ethnography unaffected. There is no overall consensus among ethnographers about the epistemology and theory of knowledge that underpins an ethnographic account, which in turn has implications for its quality criteria (Savage 2000). Instead, different ethnographies rest in different ideas of what constitutes legitimate knowledge. For example some ethnography

is based on an interpretive approach and draw on experiential knowledge gained by physical participation in the field (Spenser 2001) which others might discount as unverifiable (Hammersley 1998). Different types of ethnography have emerged drawing out the distinctions of different epistemologies and ontology. Skeggs (2001) reports some of those types, such as naturalist, realist, modernist, social constructionist and postmodernist ethnographies (Savage 2006).

A continuum approach to mapping the field of qualitative methodology might ease the tension of the dichotomous thinking between naturalistic/interpretive enquiry and realist/positivist approach. I support the view of the continuum of three main areas, with infinite possibilities for blending and moving among them, as suggested by Ellingson (2009). Aims, methods, questions posed, the role of the researcher, but also the writing style, and evaluation criteria may be considered in various ways across the spectrum from the far left of artistic/ interpretive paradigm to the middle social constructionism, to the far right realism/positivism (Table 10-2). Each of these approaches may offer different advantages and disadvantages without being mutually exclusive or having rigid boundaries. As she said, researchers should primarily focus on pursuing important research questions, regardless of the category, and less with their perceptions of what type of researchers they are.

Table 10-2: The qualitative continuum (adapted from Ellingson 2009)

	Art/impressionist	Middle ground Approaches	Realist/positivist approach
Goals	To unravel accepted truths To construct personal truths To explore the specific To generate art	To construct situated knowledge To explore the typical To generate description and understanding To trouble the taken-for granted To generate pragmatic implications for practitioners	To discover objective truth To generalise to larger population To explain reality 'out there' To generate scientific knowledge To predict and control behaviour

Methods	<p>Autoethnography</p> <p>Interactive interviewing</p> <p>Participant observation</p> <p>Performance</p> <p>Sociological introspection</p> <p>Visual art</p>	<p>Semi-structured interviewing</p> <p>Focus groups</p> <p>Participant observation/ethnography</p> <p>Thematic, metaphoric, and narrative analysis</p> <p>Grounded theory</p> <p>Case studies</p> <p>Participatory action research</p> <p>Historical/archival research</p>	<p>Coding textual data</p> <p>Random sampling</p> <p>Frequencies of behaviours</p> <p>Measurement</p> <p>Surveys</p> <p>Structured interviews</p>
Writing	<p>Use of first-person voice</p> <p>Literary techniques, stories</p> <p>Poetry/poetic transcription</p> <p>Multi-vocal, multi-genre texts</p> <p>Experiential forms</p> <p>Personal reflections</p> <p>Open to multiple interpretations</p>	<p>Use of first person voice</p> <p>Incorporation of brief narratives in research reports</p> <p>Use 'snippets' of participants' words</p> <p>Often a single interpretation with implied partiality and positionality</p> <p>Some consideration of researcher's standpoint</p>	<p>Use of passive voice</p> <p>Claim single authoritative interpretation</p> <p>Meaning summarised in tables and charts</p> <p>Objectivity and minimisation of bias highlighted</p>
Researcher	<p>Researcher as the main focus, or as much the focus of research as other participants</p>	<p>Participants are main focus, but researcher's positionality is key to form findings</p>	<p>Researcher is presented as irrelevant to the results</p>
criteria	<p>Do stories ring true, resonate, engage, move?</p> <p>Are they coherent, plausible, interesting, and aesthetically pleasing?</p>	<p>Flexible criteria</p> <p>Clarity and openness of processes</p> <p>Clear reasoning and use of support</p> <p>Evidence of researcher's reflexivity</p>	<p>Authoritative rules</p> <p>Specific criteria for data, similar to quantitative</p> <p>Proscribed methodological processes</p>

Based on the above framework, I place this study in the middle ground, as it is an ethnography situated in social construction. Hence, the study merits are based on criteria both related to the research itself and its presentation. For the quality appraisal of this study, the following criteria are proposed, as recommended by different qualitative researchers and guidelines for evaluating qualitative research and ethnography. (, CASP 2010; Seymour 2007; NICE guidelines 2012; Spencer 2001). In brief the quality of the study is reported in the table below (Table 10-3).

Table 10-3: Quality of the study

	Key quality issues and concerns	Appraisal of this study
Culture	<p>The degree to which cultural description produced, provides a basis for competent performance in the culture studied (Hammersley 1998)</p> <p>Provision of insights and understanding of the culture under study; Interpret one social group to its larger society (Muecke 1994)</p>	<p>The status of palliative care in Greece is presented and situated within the European context (Chapter 1)</p> <p>The attitudes of death and dying in the Greek culture are explored drawing upon history, social anthropology, and literature (Chapter 2)</p> <p>The context of the end of life care culture in Greece was explored by reviewing the existing health care literature (Chapter 3)</p> <p>Descriptions of the hospital and wards is offered (Chapter 6)</p> <p>The organisational culture of the hospital and attitudes of health care professionals are explored in detail (Chapter 7)</p>
Credibility	<p>Are the findings credible (Cutcliffe 1999; 2005)</p> <p>The explanation fits the description (Lincoln 1995, Patton 2005)</p>	<p>The findings are derived from the themes which emerged directly from people's reports. Participants' actual verbatim was recorded</p> <p>Strategies I followed were:</p> <ul style="list-style-type: none"> • Member check with all participants throughout the period of data collection, as initial analysis started took place whilst collecting data over time. • Prolonged engagement in the field: for 18 months • persistent observation : more than 800 hours of observation • analysis plan and data categorisation verified with supervisors at different times
	<p>The relationship between participants and researcher was reported (Savage 2000)</p>	<p>The roles adopted over time, were clearly described: from a volunteer, to a student member and a family friend (Chapter5)</p>

Transferability	Relevant to other settings (Tobin and Begley 2004)	<p>In order for the reader to consider the transferability of the findings, the context of care and of the families has been described in detail as well as the interactions, and actions of the actors.</p> <p>Findings have been presented in conferences and clinical groups and elements have been confirmed as relevant to their practice (clinical implications, Chapter 10)</p>
Dependability	Clear process of the study documentation of sampling, data collection methods, decisions, end product (Schwandt 2001)	<p>Recruitment strategy explained: purposive sampling was chosen and the reasons explained. Inclusion and exclusion criteria described ;Process of recruitment described (Chapter 5)</p> <p>Participants' characteristics presented (Chapter 6; Appendix 3) Case study illustrations used in findings Chapters. Both demographic and socioeconomic details are included</p> <p>Setting presented and justified (Chapter 6)</p> <p>Methods clearly reported: participant observation, interviews, informal discussions (Chapter 5)</p> <p>Levels of participant observation explained, interview guides presented, context of informal discussions presented.</p> <p>The process of data analysis is presented (Chapter 5)</p>
	Reflexivity (Pope & Mays 2008)	<p>My underpinning philosophy is reported in Chapter 5</p> <p>My background and professional influence is discussed in the personal statement</p> <p>Reflexive diary has been kept throughout and accounts have been offered alongside the data (findings Chapters 7-9)</p>
Confirmability	The arguments confirmed by the segments of data offered (Janesick 2000)	<p>Findings have been supported by direct quotes from all participants. Field notes and segments of the reflective diary also offered. (Chapters 7-8-9)</p> <p>The data are referenced so that the sources of the extracts can be identified: interview; field notes; reflexive diary; numbering of the interview data is also offered (Chapters 7-8-9)</p>
Authenticity	<p>Presentation of a range of different realities, (Guba and Lincoln 1994)</p> <p>Doing justice to unique cases</p>	<p>Views of the different groups and of different actors within the groups have been considered. Chapter 7 offers the perspectives, concerns and issues and values of the health care professionals, whilst Chapter 8 of the families. Chapter 9 presents the reality of patients.</p> <p>Chapter 7-8 present the issues related to a deviant case</p>

Ethics	Have ethical issues been addressed?	<p>Ethical considerations discussed (Chapter 5)</p> <p>Process of explaining the research to participants and informed consent presented (Appendix 7)</p> <p>Letters of ethics approval from both Greece and UK has been granted (Appendices 2 & 5)</p> <p>Confidentiality, anonymity addressed by using pseudonyms and changing recognisable characteristics of the setting</p>
Contribution	Does it contribute to knowledge?	<p>Findings considered in relation to current literature</p> <p>Implications for practice or policy- education discussed</p> <p>Areas of future research considered</p> <p>Limitations of the study presented (Chapter 10 discussion)</p>
	Are the conclusions plausible and coherent	Final conclusions are presented at the end (Chapter 11)

10.2.1 Strengths

The choice of ethnography as the methodology of this study empowered the research with the flexibility in using different modes of data collection- participant observation- interviews, informal discussions- but also adapting those chosen, in order to collect high quality data. The ethnography allowed the data collection in the natural environment in which aspects of care and experience of care and illness evolved over time. By observing actions, reactions and behaviours among participants, the culture of the specific setting was revealed (Schneider et al 2007). The ethnographic framework allowed me to be physically present in the hospital setting and thus, with participants for longer periods, than of that of an interview study. Indeed, the ethnographic approach allowed me to see what people actually did, not only what they said (Atwal & Caldwell 2005). By observing the care firsthand, in the context where it was delivered, I was able to put together actions, perceptions, views and interactions and learn about the participants' social practices and relationships; practices and dynamics between health care professionals, families and patients (Moore and Savage 2002).

Comparing to other ethnographies in clinical settings, the primary focus of data collection was with patients and families and then radiated out to nurses-doctors and structural aspects of services. Instead of organising fieldwork around the health care professionals work and structures (e.g. Atkinson, 1995; Lawton, 2000), this study's fieldwork was primarily family-patient centred, whilst extending antennas to the health care professionals. I primarily followed the family rota instead of the nursing schedule; I stood next to the patient waiting for the nurses and doctors to come and interact with them, and secondarily followed the medical rounds and nursing calls- apart from the first three months of fieldwork when I was establishing my presence in the field (see more in Chapter 5). This approach allowed me to understand better the family patterns and roles (Chapter 8) and discover the leading role of patients in the dying phase (Chapter 9). At the same time, I explored the views of the health care professionals who came in contact with the patients- families participants. This way, the collected data gave the option of multi-faceted perspectives to be revealed, and hence supporting the desired multi-vocality of the social reality of dying in the hospital (Grove & Burns & 2012).

My different roles developed during participant observation and the flexibility between non participant observation/ participant observation (see more in Chapter 5, Section 5-9) facilitated a richer data to be collected (Bloomer et al 2012). By immersing myself in the field for eighteen months, I was able to develop a better understanding of the reality of the hospital under study and I managed to develop a reciprocal relationship with participants, and collect their views and concerns at the time, prospectively (Griffiths 2008). Additionally, as the fieldwork progressed, I realised that I would not be able to collect the patients' views during set times of the interviews. Thus, I was able to adapt in recording informal discussions at the bedside, at the time they occurred. This way, patients were able to answer questions I needed to explore further, but also present issues with priority and importance for them at the specific time. This mode of collecting data from patients

proved to be important in understanding their concerns and preferences, but also helped in tracking the changes of views, preferences, concerns and wishes over time.

Also, capturing the interaction between participants in real time is a strength of this study. My presence -at the time events occurred- was a great advantage as I was able to capture patients' negotiation of care with their families and preparations of dying. I was able to record the dialogues in which diagnosis, care plans, concerns over symptom control and choice for place of care and place of death were communicated. Capturing the actual interaction and compare them with participants' interpretations and reasoning, gave me the opportunity to unpack the decision making and its reasoning over time. The recording of those interactions confirmed what people argued in relation to expectations from each other, and the power hierarchy. An attempt for a linguistic analysis of the verbatim between patients and their families and between patients and health professionals, confirmed the findings of the power dynamics between the groups and their expectations from each other (Appendix 8).

The combination of participant observation, interviews/ informal discussions and patient documents worked complementarily rather than competitively, whilst their exploration offered the possibility of their crystallising. They were not used in validating each other, but instead, they offered the possibility of examining findings from different angles, as other ethnographers have posed (Staton et al 2001; Murphy 2005). Any contradiction between different accounts was treated as a real chance for more comprehensive explanations and understanding of the differences in the reality experiences of the different players. Such contradictions offered me the opportunity to explore further the obvious and seek for deeper explanations and meanings of the not obvious.

Lastly, this study followed the actual timeline of the patient trajectory, not an artificial one, selected by the researcher. This is crucial for capturing longitudinal aspects, such as changes over time. Instead of a pre-set data collection (e.g. 6, 3, 1 months before death), as

interview and survey studies have followed (Murray et al. 2006; Murtagh et al., 2011), the ethnographic framework allowed an 'on call data collection', which might be more sensitive in understanding the patient journey and capturing the changes taking place but also explore the reasons behind.

10.2.2 Limitations

This work focused on the lives of a small group of cancer patients (13) and their families being treated in a specific clinical setting. It is a study taken place in one specific hospital setting, conducted by one researcher. It is not therefore possible to confirm if the findings of this study are relevant to other settings (home- hospice care- other hospital settings) and different cities/ communities, although participants were chosen to come from both urban and rural places. Therefore generalizability of the findings cannot be claimed. At the same time, the choice of fieldwork in one setting and a small sample, but with repeated data collection over eighteen months can be considered a strength as it resulted in highly detailed data and analysis and enabled a rigorous and in depth exploration of the culture of care and participants' experience over time (Savage 2000).

Despite the efforts made for a purposive sample- covering as much diversity as possible- I did not observe very dysfunctional families. As patient recruitment was only successful through their families (see more in Chapter 5, Section 5.8), perhaps a bias has been introduced in relation to dysfunctional families, as perhaps those families would object to participation in the research. At the same time, this proves the importance of the families as gatekeepers and their crucial role in the patient care.

The centre of the study was more with the families and patients and less with health professionals, hence no deeper understanding of the health professional experience was acquired. Although professionals views are well represented in the interview data and their actions are documented through participant observation, I have not obtained data on the 'backstage' nature of professionals' work (Atkinson 1995) in providing cancer care to

these patients. As a result I am unable to provide detailed ethnographic insights into the professional domain that examines the process from their standpoint; their thinking, and reasoning behind the scenes and how they developed their decision making at the time.

Another limitation of the study is that it is focused more on the interactions, rather than other elements of the experience, such as psychological aspects. As the study was situated with social construction, the interactions between participants were given priority. It would have been actually very difficult to get this three- dimensional depth in the time frame and resources I had for this study.

Despite my intention to focus on patient interactions, I mostly recorded families negotiating with patients and health care professionals and less between patients and health care professionals. There is limited evidence of communication patterns and dynamics in relationship between health care professionals and patients, whilst the family chapter explores communication much deeper. However, this is a finding on its own, as it underlines the mediator role of the family in communication. On the other hand, patients' leading role in communication evolved during the dying phase (See more in Section 10.5.4).

10.3 End of life care and decision making

10.3.1 Care culture

The study findings suggest that the care provision was rooted upon the notion and structure of a biomedical model of care. The culture of the hospital being developed around the cancer disease was oriented towards curative treatment; aggressive treatment of cancer, and less focused on holistic care (Bio-psychosocial model). As Wade & Halligan (2004) argued, cultural beliefs and models comity of illness reflect the perceived importance of illness, symptoms and subsequently the use of medical resources (Wade and Halligan, 2004). Indeed, in the hospital under study, most of the resources and facilities were allocated for the active treatment of cancer, whilst the psychosocial services

received minimal support, as only two professionals were staffed to cover the relevant hospital needs. Also, the longitudinal data disclosed a very limited time and space for transition to palliative care and dying preparation, as care provision was dominated by the focus on cure and prolonging life until the very late stages of the disease.

Moreover, the structure of the care services gave emphasis on the system and not on the patient, and inflated extreme bureaucracy. As presented across the findings chapters, all groups of participants complained about the system bureaucracy, the lack of services co-ordination, and the need to demonstrate creativity, patience and endurance whilst navigating through the system. The hierarchical structure of care provision- determined by the doctors- reflected the professionals' attitudes and collaboration with each other, highlighting several power-balance challenges over time. No teamwork was observed.

The biomedical nature of care was also manifested in the health care professionals' perceptions, as they identified their roles with defeating cancer, and not with other aspects of care. Doctors in particular, confirmed the focus on disease and treatment, and explained in their interviews that supporting quality of life and patients' psychosocial needs could not be part of their job, rather than a private matter that the families had to deal with, especially near the end.

Although the expression of those elements of hierarchical care were particular to this cancer setting, the nature of this care system appertains to all health care in the Greek context. A study about organisational culture in Greek hospitals, confirmed that hospitals in Greece are characterised by hierarchical cultures, mechanistic approach of function and task oriented care (Chondrocoukis & Papageorgiou 2010). A number of studies by Bellou related to hospital culture and job satisfaction reflect the above characteristics. She reported that health care professionals believed that willingness to introduce new developments, different patterns of care and teamwork practice were least valued in their organisation (Bellou 2007; 2008; 2010), whilst following the rules, and being careful and

precise in the tasks operation were most valued. Kastanioti et al. (2011) reported similar values, and only added the values of adaptability to existing circumstances and tolerance as equally valuable.

The hierarchy of power and dynamics reported in this study, have also been presented in a study by Lentza et al. (2013), using focus groups between doctors, nurses and patients; she found that all parties experienced challenges of power. The authors reported that patients felt powerless against the dominant, powerful physicians who expected them to accept their interventions with passivity; witnessing the battle between nurses and doctors was reported to have a similar effect. Similarly, doctors reported feelings of helplessness, considering themselves as victims of a dysfunctional system and a powerful management, having no space or power to make any changes. Interestingly, nurses' views and experiences were not presented, although in findings' discussion they were grouped with doctors as health care professionals. This might make an indirect suggestion about the place of nurses within the hierarchy of the system and the lack of power to make their voice heard.

The findings of this study may highlight a distinctive feature in relation to doctors' position in cancer care; notably their vulnerability. Despite the power doctors had in terms of hierarchy within the hospital structures, they still said they felt threatened by the undefeatable cancer, but also by the families' force- not by patients. They had to be this entire knowledgeable person who was somehow in charge, but actually they were challenged by the illness- which anyway they could not cure- ; but also by the families who disputed their decisions when disagreeing. When such conflicts arose, doctors felt undervalued and not appreciated for their expertise, whilst feeling that they were forced to compromise with unwelcome choices. Such an example is Sila's care near death, where her doctor felt he was forced to perform a puncture, under the family pressure who threatened to sue him for not trying his best for their patient.

The length of illness- at least some months- and deterioration from it might contribute to this situation. When exploring the data over time, I found that families became more challenging towards doctors, albeit at the beginning they were a lot more compliant. Several possible explanations might address this observation. First, the encounter of families with the health care system and the health care professionals was lengthy (at least some months), and inevitably a relationship developed between them. Perhaps this enabled families to express their challenging thoughts more open over time. Secondly, families who were heavily involved in the care provision developed a certain expertise over time in dealing with the health care system and the professionals' dynamics. In addition to the acquired knowledge over time, families' sense of duty for advocating for the patients might have increased their confidence in challenging the care provision. Family's challenging behaviour might also be related to the transition of families' preferences from cure to fulfilling patients' wishes; this is discussed in section 10.4. Finally, the anticipation of the death outcome with its' involving stress and anticipatory grief might inflame greater tensions.

David Clark (2010) defined this conflict as beneficence tension. He described it as the conflict resulting from the internal desire of each member involved in clinical encounters to search for, according to their own perspective, the most beneficial outcome for the patient. It therefore refers to tension of good intentions and not between competing ethical principles. Depending on the outcome, these encounters have the potential for both professional fulfilment and frustration. This concept could have important implications for palliative care. Such conflicts can be met frequently in palliative care, due to its nature of being fundamentally relationship-centred work (Smith et al. 2007). The findings of this study showed that beneficence tension was observed particularly near the end of life, between doctors and families when perceptions of quality of dying and death were negotiated for patients.

When the relationship between doctors and patients or families is severed, the former might feel that they have failed in one of our most important tasks, and this perhaps might offer an explanation of their sense of vulnerability (Smith et al. 2007). Notwithstanding, beneficence tension is discussed in relation to the encounters between doctors and families/ patients, similar conflicts can be anticipated between nurses and doctors or other health care professionals. Possible areas that professionals should anticipate beneficence tension can be physical, psychosocial, spiritual and existential experience, life closure, death preparation and the circumstances around death (Hales et al 2008; Stefanou & Faircloth 2010).

The acknowledgement of beneficence tension might help disarm the self-protective barriers that patients and family members raise when they perceive a lack of validation for their perspectives (Clark 2010). Also, nurses and physicians have the potential to communicate better when both affirm their desire for the best patient outcome, even though the opinions about achieving those outcomes may differ. Perhaps a model of care where doctors remain the expert but a fallible expert, and where families are accepted as equal partners might have potential. Families and professionals' dynamics is discussed further in section 10.4.

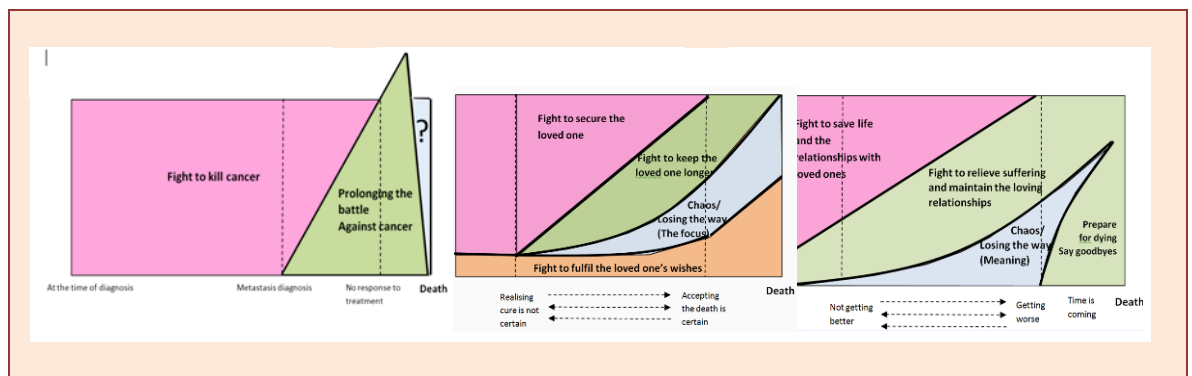
10.3.2 Decision making of care over time

This study provides a unique three-dimensional perspective of the experience of care and illness for patients with advanced cancer, as it captured the views and preferences of the participants prospectively until patient death. In an effort to capture the nature of care, the decision making between patients, families and health care professionals was documented, as it evolved overtime, whilst addressing the ever upcoming challenges of the reality of dying from cancer. What is unique in this study is that I looked at the different perspectives overtime concurrently across the groups and that enabled me to explore how differently the three groups understood and operated within the patient trajectory. To my understanding no previous studies have investigated these differences,

while several studies only explored one group or gave a cross-sectional view (Burns et al. 2007; Werth & Blevins 2009, Pardon et al. 2012a).

The decision made about care overtime, reflected changes in preferences and choices of doctors, families and patients. These in turn revealed some possible patterns of mindset shift which grew differently across patients, families and doctors (Figure 10-1).

Figure 10-1: Trajectories of experience and of decision making focus over time for doctors, families and patients



The figure reveals a number of issues: i) time is important; that there are some changes happening over time; ii) It also shows that there is a main orientation in life over time, a mindset of priorities at different time points that may inform decision making; iii) patients, families and doctors do not necessarily follow the same orientations and that their priorities do not necessarily match; not at least always. Another study by Burns (2007), which explored perspectives between families and patients, found that 40% of the pairs of patients -families had different perspectives on the goal of treatment at the end of life.

When comparing the doctors/ families/ patients longitudinal figures, we can clearly see their differences in their focus of decision making. Physicians focused on cure and prolonging life until the late stages in the illness trajectory. The more the disease progressed and the patient's response to treatment failed, the more the doctors intensified

their efforts, allowing little opportunity for the transition to the palliative phase. This finding illustrates the biomedical and hierarchical structure of care provision revealed in this study where physicians mostly focus on physical and curative issues (Wade and Halligan, 2004). Meanwhile families' orientation seemed to be influenced by both doctors and patients. Their decisions aimed at supporting choices towards cure and preserving the relationship with their loved ones initially. However, the more the illness progressed, the more they shifted towards meeting patients' needs and made decisions in support of patients' wishes. This shift might be encouraged by the increasing awareness of dying as shown in the study of Burns et al. (2007). They found that the time family spent accompanying patients had positive influence on family's awareness of dying and that awareness of the proximity of death was acquired by their interaction with the patients. Nevertheless, the study could not identify specific signs, processes or interactions in support of this, perhaps due to its cross-sectional nature.

Patients on the other hand seem to focus more on the relationship with their loved ones, and thus their decisions were supportive of their families' wishes initially. However, the more the symptom burden increased along with the condition's deterioration, the more they focused on relieving their suffering and the more they desired to keep their families close. This inclination has been confirmed by other studies in different settings, such as Canada and USA. Rodin (2009) looking at this behaviour through the attachment theory lenses, he named it 'attachment security at the end of life' and argued that maintaining close relationships with the loved ones, can secure emotional wellbeing and better adjustment to the ongoing changes. Nevertheless, the findings of this study supports Lawton (2000) ethnographic work and view that close bonds with the family, may enhance the integrity of the patient's identity as it is realised through the familiar relationship. Dying phase was initiated by patients who fought to secure space and place for preparation; patients lead the dying rituals, showing therefore that the dying phase is not a passive period which entails patient's acceptance of death, rather than an active

phase which involves patients' own constructions of dying. The incidence of dying rituals identified in patients with a strong Christian affiliation has been also reported by Werth & Blevins (2009). A few ethnographic studies conducted in Canada and the UK, which observed patients at that stage, do confirm the existence of active preparation and dying rituals, often ignored by health care professionals (Armstrong-Coster 2004; Staton et al. 2001). These studies therefore may suggest that an active preparation of dying might be relevant to the human nature and not only unique to the participants of this study. However, the lack of studies looking specifically at the dying period might allow false assumptions of its passiveness.

Awareness of disease progression

Awareness of the disease progression was approached differently by doctors, families and patients. The family's position in decision making was in the middle between patients and doctors and their position on balancing between doctors' choices and patients' wishes became apparent. Doctors understood the disease progression and decided upon care based on their diagnostic indicators of tumour progress- metastasis and response or not to treatment. These indicators have been found to be similar to those influencing doctors seeking palliative care consultation for their patients (Tilden et al. 2009). Similarly, Shell and O'Hare looking at patients with advanced kidney disease, reported that doctors assessed patients' trajectories using similar criteria, based on which they communicated illness progressions with patients (Schell & O'Hare 2013). Therefore, it is not just the Greek doctors who assess illness progression based on diagnostic criteria but doctors across systems. However, Greek physicians might be faced with increased challenges, as there are only a few and very limited palliative care services and thus they cannot receive guidance and support. Perhaps this explains their confusion about treatments goals at the end of life.

Families seem to base their approach at first on the information given by the doctors (i.e. cure is not certain). But the acceptance of the certainty of death and therefore their shift

into focusing on fulfilling patients' last wishes derives from the signs they receive from the patients; from patients' experience of their deterioration who at the time lead the dying phase. The role of the family as a bridge in the communication between patients and doctors was identified in a health culture of family centeredness by Lin et al. (2012). However, the shift of family's mindset overtime between doctors and patients' preferences at the end of life was not explored. Patients of this study, on the other hand, could not rely on information as there were not informed about the disease progression and of their prognosis. Their orientation and preferences over time were based on their own experience of deterioration, from not getting better to getting worse and eventually dying. Family's relationship with patients and professionals, and patients' trajectory is discussed further in section 10.4 and 10.5.

Family's balancing role between doctor and patient

Perhaps families' position as negotiators between patients and doctors preferences and choices, might explain the nurses and doctors attitude, according to which families can be both of a supporter and a barrier. It might be that when advocating for doctors' decisions they become supporters but when they challenge their choices by giving priority to patients' preferences, they might be viewed as a burden and a barrier. Families therefore might become supporter and barrier at the same time when negotiating a balance between different preferences, or at different time points, when their orientation shifts from the viewpoint of the doctor to the one of the patient. Despite the challenges, families appreciated the role of balancing act, as they considered it their duty; an aspect of their loyalty towards the patients.

Power dynamics in decision making

This approach to priorities and decision making over time showcases the complexity of decision making as a process. It takes into consideration the several actors involved, potential change-triggers and influencing parameters that lead to change of preferences,

or change in the hierarchy of priorities. Hence, this framework can be quite flexible, as it recognises parallel focuses and preferences. Power dynamics between the groups, not only influenced the relationships but also the hierarchy of priorities (i.e. whose priority comes first) and therefore the decisions made. More specifically, at the first stage the doctors were the main leaders and all decisions focused on defeating cancer and curing the patient. During that period, not much conflict was witnessed, as both families and patients' orientation was congruent. However, during the second phase, family gradually took control, and thus decision making which referred to symptom control and quality of life was progressively introduced. At the final stage, patients became the leaders of decision making, shifting decisions around dying preparation, place of care and death, and securing conditions for death rituals' implementation. Hence, it could be said that decision making was not solely centred towards one group or another, rather than changed depending on the prevailing factors- including the dominant decision maker- and the stage of illness. A cross sectional view of the power of decision making in the literature suggested three types of power dynamic identified in individual cases: namely doctor control, shared control and patient control (Pardon et al. 2012a). However, according to the findings of the present study these three types of decision making can occur within the care of the same patient, but in different stages of illness progression.

This leads us to consider the levels of participation in decision making. Levels of participation might explain findings which seem contradictory at first level.

The fact that a main orientation was identified at different stages of illness does not mean that other preferences were not present and pursued. Indeed, a shift of orientation did not mean abandonment of the previous preferences, rather than a shift of their hierarchy and therefore priority. For example, as seen in families' diagram, at the final stage whilst their orientation was to fulfil patients' wishes - which at the time were preparing for dying- they still strived to secure patient's life for as long as possible, by not interrupting cancer treatment. Or when patients' priority became the relief of suffering and symptom control,

they still hoped for cure. Rodin (2009) argued for the existence of “double awareness” in the terminally ill patients where patients hold onto an awareness of survival and death at the same time. Such ambivalence not only maintains patients’ hope of living but also prepares them for death. This notion might be also applicable to families and it might explain family’s mindset as demonstrated here. This knowledge might prevent professionals from fragmenting patients and families as to only a receiver of medical treatment. Patients and families live their life in the meantime, and decisions for treatment and care are only one aspect of it.

Patient’s Autonomy and family-centred care

At first level it seems that decision making was either doctor centred or family centred and not patient centred, therefore patient’s autonomy was not respected. Yet, it might be that autonomy is displayed in different ways in different systems (MacKenzie & Stoljar 2000). For example, patients displayed their autonomy to families, as they believed it was their right to have their families helping them, and hence they did expect their families to care for them, an expectation confirmed by Lin et al. (2012). They displayed autonomy by asking their families to be close to them, as expected and believed they had the right to have their families close to them. That could be an expression of autonomy, but not the kind of ‘I am the individual’ and I decide what happens to me. Instead it might be the notion of ‘I belong with my family’ and they come with me and I may make decisions that are best for all of us, not just for me as this is more important. It comes from a different world view, a more collective organisation. Data showed that patients actively negotiated with their families over time and were able to demonstrate that, with the strongest expression of leading their dying: for example, even near the end they wanted their family to be with them but not talk; or they wanted to make sure certain things are done in order to die. This might be comparable to Chinese culture where the concept of self is related to others (Armstrong & Swartzman 2001). Indeed, in the Chinese health care

culture, decision making is primarily family centred and utilises the family as a whole (Lin et al. 2012).

However, such a notion of autonomy should not be generalised, as not all patients identified with it. For example, Yiannis behaved very much as an individual, occupied by his personal rights and needs and his expectations from a health care environment to understand and serve them. His personhood consisted mostly of his self and less of social relationships. His preferences and thoughts were very distinctive to himself and his autonomy was one of his main concerns. Therefore, individuality in each patient should be still considered in the clinical setting.

10.4 Family: a system approach

10.4.1 Family care-giving roles

Families proved to have a central role in care provision and in the life of the patients. They were instrumental in both care giving and decision making of care over time. They adopted a variety of roles from provision of bodily care and support, to assessment of the complex structures of the system, and to co-ordination of services. The importance of families to quality of care at the end of life has been increasingly acknowledged, shifting the focus from the patient to the family and patient as the unit of care (McMillan et al 2006).

The findings of this study showed that families understood their role as being present 24/7 next to the patients, and as keeping their ill member loved and protected at all times; alleviating patients' suffering induced by the disease, the symptom burden and treatment regimens, but also the truth of death prognosis which they perceived to be a useless form of cruelty. (See more in Chapter 7). Research evidence from across the world, has offered similar findings in terms of family's roles (perception and actualisation), suggesting that families across countries and health care systems do adopt such a variety of care-giving roles for their ill members. A systematic review on families' roles as seen by the families

themselves, described three broad categories of roles: being present, securing good patient care; and communication with health care professionals (Andershed 2006). Similarly, the National Cancer Institute in the US produced a report regarding family caregiving roles in cancer, identifying five major roles: decision-maker; advocate; communicator; hands-on care provider and social support (NCI, 2012).

Looking at the caregiving literature more carefully, it seems that the differences of roles found amongst the studies, were not about the concepts of main roles but the actualisation of those roles; more specific, how and where these roles are executed; the level of family involvement, and the spectrum of tasks these roles entail. For example, hands-on-care has been described as the provision of basic care both in hospital and at home but elsewhere was associated with mobility support (Emanuel et al. 1999; Given 2001). Advocating for the patient has been described as voicing patients' wishes and supporting those (Payne et al. 2010); but in others as also mediating for pain management and symptom comfort, tasks undertaken by the families of this study as well (Ferrell et al. 1991; Hudson 2004). In this study, advocating also meant controlling the information given to the patient, and protecting them from the truth of the prognosis; making decisions on behalf of them, attitudes found also in Spanish and Italian studies (Fainsinger et al., 2003; Locatelli and Piselli, 2010).

However, even in this study where families considered their duty to provide hands-on-care to their ill member, they were not prepared to undertake such a wide spectrum of roles and to such an extent. Particularly the areas of co-ordination of services and administration support were not always welcomed and not by all families. Improvising in these areas, due the gaps in the health care system was often described as overwhelming; not only due to the energy and resources required, but because this inevitably meant less time next to ill family member. The efforts and struggle in accessing and co-ordinating of services have been reported across the borders; in the UK for patients with MS (Edmonds et al 2007) and it was called 'fighting for everything', in Canada (Tallman et al.

2012) which was called “timely access to coordinated medical care” and in Italy (Marzano 2009). The above findings therefore, might suggest that families’ adopted roles do not always reflect their preferences for care provision, but instead their wish to protect their family member from the inadequacies of the system and the inefficiencies in the available resources.

Despite the challenges, families claim to value their care giving role. As other studies reported, families in this study gave positive attributes to their experience: feelings of satisfaction of fulfilling their role as families (Hudson 2004), gratefulness for being able to provide for their loved ones and reciprocate the love they had previously received from them (Stajduhar 2003); gaining a new life meaning and personal growth through this experience (Strang & Strang 2001; Koop & Strang 2003; Oldham and Kristjanson 2004). These findings suggest that families value the importance of their roles, despite hardships and burden they also experience.

A number of implications may derive from these findings. Families perceive themselves as having responsibility of care towards their family member and perhaps they need to be allowed to fulfil their roles (Broom & Kirby 2012). It might also be that families are not willing to get involved with all aspects of care, but as noticed in studies in different countries and systems, families undertake different aspects of care, in an effort to counterbalance of the system’s gaps. This effectively means that the different roles families assumed in different countries, do not necessarily suggest different cultural norms. Instead, they might mirror their adaptation to the existing structures of health care provision by compensating for its inefficiencies.

Palliative care providers need to be aware of the different roles individual families prefer or feel capable/ comfortable to deal with, and enable them to contribute to those aspects of care they wish to be involved. Corresponding to families’ preferences, palliative care services need to provide those aspects of care that families would not wish to be involved

with and support the level at which families want/ can contribute. Implementation of palliative care services should equally consider the existing health care structures, and the expectations of the system towards families' involvement. This in turns raises more challenges, discussed below.

10.4.2 The balancing act of power between families and health care professionals

Another important issue deriving from the findings is the ambiguity of the family place/ role in the patient care in relation to the other contributing actors of care provision. The findings showed that families were so integrated and so segregated in the care system at the same time. They were viewed and treated as much as members of the care provision system and yet so they became a burden, barrier; revealing a fascinating contradiction in perspectives which fed into several communication tensions.

To be a good family you would need to do the washing, bring the food and you would be expected to make sure that the appointments are particularly organised. Families were expected not just to contribute to basic care, but also to manage and organise it. They were expected to provide such a multifaceted care (See more in Chapter 7; Sections 7.4.4-7.4.5), and participate at the level of co-ordination of services. However they could not become partners. For example they were asked to leave patients' rooms during medical rounds or examination/ interventions, and not challenge doctors' choices. As soon as they demonstrated that they were actually equal and claimed an expertise in patient care, then they were viewed as problematic, and were pushed away by the nurses. These findings, hence, suggest a somewhat different sight in relation to family's involvement in patient care. Prior studies have reported dissatisfaction of families due to their insufficient involvement in patient care (Andershed 2006; McLeod et al 2010). However, this study shows that the problem might not be their involvement as such, but their equality in participation. They wished for their contribution and expertise of knowing the patient best to be acknowledged. And thus they wished to be accepted as equal partners in the health care team. Interestingly, nurses presented with similar

complaints when discussing their relationships with doctors and their struggle of being treated as equal members of the team. Yet, they reproduced this pattern in their relationship with families.

These findings can be explained under the concept of hierarchical structure of the service, and the prevailing power dynamics where doctors are at the top of the pyramid, followed by the nurses, and perhaps then by the family. It might be that families are accepted as parts of the care structure, but not as equal members of a team. Hence, families could and were expected to perform their tasks, but follow medical and nursing instructions without challenging their ways. Families therefore were faced occasionally with the terrible dilemma between actively advocating for the patients and following the instructed care by doctors and nurses even if they did not agree, in order to maintain their role in care provision and their influence on the health care team; doing the right thing but also keeping health care professionals happy. For example, when Pablo's wife initiated communication with the orthopaedics department to secure a timely operation for Pablo's hip fracture, Pablo's doctor furiously suggested that she had overstepped her mark, despite the fact that she did the right thing. Although she had actually helped the doctors with a troubling communication, she was expected to keep a low profile and not claim credit for it (See more in Chapter 7, Section 7.3.3). Hierarchical care therefore, was not challenging only for the members of the health care team, but also for the families and their function as carers.

10.4.3 Family function- system approaches

The findings of this study throw some light onto the family function as a system, due to its ethnographic nature and the observation of family' interactions and involvement in patient care as it evolved overtime until patient death. This is very important, as there is very limited work done on family interpersonal dynamics and decision-making. Whilst much of the work has focused on identifying family's needs and ways of enhancing family support mechanisms, research studies have failed to capture the entire family system,

limiting the perspectives to one single member, often chosen to be the spouse (Mehta et al 2009; Hudson et al 2004, Reimer et al. 1991). Yet, as Broom and Kirby (2012) found, the dying process entailed considerable tension around the patient wishes and family structures and values.

This study showed that the family's involvement in patient care was not only multifaceted, but it also involved multiple family actors and different levels of responsibility. Indeed, most of the times, more than one family member was actively involved in the patient care. Family members shared roles and duties whilst engaging at different levels of responsibility. To make things more complicated, the family relationships dynamics were proven not to be linear when the data was examined overtime. Different carers were in charge at different time points and even more, not in all aspects.

Indeed, little is known about the interplay of family dynamics with palliative care provision (King & Quill 2006; Mehta et al. 2009). This study showed that the family operated as a system; a set of interrelated and interdependent individuals with their own rules of functioning, which unavoidably informed the family caregiving role- an added role into the family system. In fact, all families-participants, shared a variety of responsibilities, which can be grouped in two loci: the locus of decision-making and locus of caregiving. The family members were allocated into one or the other group of responsibilities, and performed their tasks accordingly. The data revealed that the allocation of the different roles to different family members did not happen randomly. The prior dynamics of the family system and other existing competing roles appears to have informed the allocation of roles and tasks in relation to patient care. To be specific, the dominant members adopted roles under the locus of decision making (co- ordination of care, important decision-making and communication with the doctors), whilst the rest retained their supportive roles under the locus of care-giving (provision of basic care; day to day decision-making; informing the broader family; doing administrative work such as authorising prescriptions and other back up tasks, such as preparing food for the patient

and bringing clean clothes). Thus, as Wright & Leahey (2005) supported, the change in one family member- namely the patient, showed to affect the entire family system which changed and adjusted their functioning over time in order to accommodate the ever changing family reality with the loss of their ill member in the end. If health care professionals were aware of those patterns of function, they would be able to address the relevant issues to the right members of the family. Doctors could address issues around illness progress and treatment decision making with specific members of the families responsible for those matters; and nurses could address issues around care and support to the caregiving members who were responsible for the day to day care provision. This might be a way of supporting a more effective family centred care (See more in implication section, 10.5.6).

It should be said that family patterns were not stable but did change over time, whilst illness progressed and other family events interfere. Within the thirteen family cases I followed, four patterns of family function were identified over time related to the change of roles (Chapter 7, Section 8.4). The data on family function overtime revealed that dynamics were challenged mostly when changes happened within the locus of decision making; when the dominant family members became unfit to fulfil their roles for a variety of reasons. These changes resulted in changing of the course of treatment, the focus and place of care, the place of preparing for dying in different cases. These findings might suggest a hierarchy of roles within the family, placing higher the decision-making, co-ordination of care and communication with doctors. These roles were also proved to be more critical in terms of family stability and family orientation over time. Perhaps, we should give priority in supporting those critical roles which are important to family stability.

The above findings offer another insight into the family function. They showed that families are trying to create a balance between change and stability, when new circumstances emerge; related either to patient illness or to the family unit. Indeed, as

soon as the critical roles were challenged, families sought to re-organise their system by introducing new actors into the stage or re-arranging the roles and responsibilities; perhaps in an attempt to maintain their equilibrium and secure the continuum of best patient care. Studies looking at the family function from the psychiatry field (Sholevar & Perkel 1990); the paediatric field (Cummings 2002), and critical care (Goodell & Hanson 1999) have addressed this issue, named as family homeostasis. Nevertheless, this concept has not been explored in palliative care, where constant changes occur over time. Another issue that should be flagged here is that not all families are well functioning and supportive towards the patients, thus able to get re-organised every time they are faced with new challenges. Palliative care research would probably benefit from addressing this area, and explore further families' systems and patterns of function over time.

10.4.4 Relationship between family and patient.

The findings of the study highlight the impact that hands-on-care may have in the relationship between families and patients; the more the family provided hands on care, the more they identified themselves as a unit with the patient. The notion that describes the family as a unit with a patient might be seen also as the patient being the extension of the family body.

The more the patient became dependent, the more the family took over the personal care and the more they undertook decision making and advocate role for the patient. At first level, that might be interpreted as patients losing the autonomy of their individuality. But on another level it might be that such an attitude safeguarded patients' identity. Although patients were losing their body, they maintained their social roles in the family, and thus maintained their identity until the end. The family proved to have a crucial part to play in this, as they were the ones that supported and fostered the social roles of the patient, since they considered them as part of their unit and not as something outside of them.

To deliver the best care, we need to understand that the patient is immersed in a context called family, an interactive system. Death and dying should be perceived as a family event that likely throws all family out of balance and requires adjustment of all family members, not just the patient, into the new reality. Future research should give attention to this area.

10.5 The 'over time' element- longitudinal perspectives of patient trajectory

As this study aimed to capture the experience of illness and care over time, it revealed views and preferences, wishes, goals and decision making as they evolved throughout the patient journey until death.

In particular, the present study offers a distinctive perspective of the advanced cancer patient trajectory because it presents insights of the longitudinal experience of the last months of living with cancer through the patients' own eyes comprehensively. Indeed, rich and thick descriptions regarding patients' own understandings, goals and priorities and the influence from those people around them were discovered. This is important because understanding the experience of dying people has been limited thus far by the relative lack of longitudinal studies in the field (Steinhauser, 2005). Although cross-sectional and retrospective studies have increased our understanding of the experience of advanced cancer, they cannot address the complex dynamics of the patient's experience from diagnosis to death (George, 2002). Longitudinal research may accurately illuminate the experience of dying individuals over time throughout the trajectory of their illness. (Nissim et al. 2012).

Although palliative care research has started exploring the changes over time in advanced disease, it has primarily focused on the physical aspects of the trajectory (Murtagh et al. 2004, Lynn & Adamson 2003; Murray et al 2005; 2007). Little has been done to explore the patient experience over time and even less to explore patients' own assessment and understanding of living with dying until death. Research on death and dying stemming from social sciences and psychology have addressed three main areas of psychosocial

experience of death and dying with cancer: a. adaptation to cancer progress and dying (Parkes 1989; Dobratz 2002; Manne & Badr 2008), b. communication and awareness of diagnosis and prognosis (Seale 1991; Field & Cope 1999; Johnston & Abraham 2000); and c. trajectory process of dying (Glaser & Strauss 1968; Armstrong-Coster 2004). Even so, the theories developed reflect mostly the health care professionals, researchers, and educators' point of view. Theories of dying tend to be etic rather than emic (Corr et al 1999). Experts have organized their observations, assumptions, and speculations into attributions about dying people. For example, the theories of Kubler-Ross (1969) and Pattison (1977) more directly mirror the viewpoint of the health professional rather than that of the patients and within this stance focus on ways in which professionals shape ill individuals' reactions into "adaptive" and "appropriate" outcomes (Corr et al., 1999).

In contrast with the trajectory literature, all dying theories developed have not taken into full account the physical reality of dying and have looked at specific dimensions of dying in isolation, thus lacking the multifaceted experience of dying as well (Buckman 1993; Copp 1998). The study by Corr (1992) was the first step in addressing the multi-dimensional aspects of dying, taking into considerations the physical, psychological and spiritual aspects of dying, including the responses of health care professionals. The current study, having identified this gap, has explored the interaction of the different dimensions of dying, and offers new insights into the longitudinal experience. A few ethnographic studies which explored aspects of the experience longitudinally will be discussed along with the study findings (Staton et al. 2000; McNamara 2001; The 2002; Armstrong-Coster 2004).

10.5.1 Awareness of disease progression over time

Although previous research has indicated that patients develop death awareness, and although disclosure of prognosis is now considered as good care practice in palliative services (Field 1996; Seale et al. 1997, The 2002), health care professionals in acute setting in Northern Europe and the US and most professionals in Greece still do not communicate such information. The findings of this study show that patients gradually

develop awareness not only of their imminent dying but also of the illness progress over time, irrespectively of the provided information. Indeed, even when families and doctors did not support the disclosure of prognosis- patients were aware of their situation.

As presented in Chapter 9 (Section 9.4), patients realised the progress of the disease, drawing from their experience of their body. Patients knew because they were not getting better and later only worse, despite the reassurance received from doctors and families. Two weeks before death they started talking about dying. Expressions of patient' s awareness such as *'I see I am not getting any better'* or *'I think my body is giving up on me/ my body is deserting me'* or *'I can see that I get weaker and weaker day by day'* were used by the majority of the patients during interactions with me or their families. Similarly, Copp (1998) in an ethnographic study with dying patients reported that patients 'watched' for their physical fading which involved bodily deterioration, social fading which involved withdrawing from friends and family; and personal fading which involved a negation of the individual by others and patients own contemplation of personal mortality.

Also, observing other patients with similar illness trajectories was informative for their situation. Comparing themselves with fellow patients with the same diagnosis but in more advanced stages, initiated concerns about their personal prognosis. This is very similar to the findings of Bluebond-Langner (1978) of the children dying world, as children patients were not told about their prognosis but very similarly understood their process. Bluebond-Langner (1978) said that the children were not told that they would die, but they knew because they did not get better, because they saw other children who did not get better and understood that they would not get better either; they knew they would die. Patients did obtain understanding of the illness progress through experiencing the deterioration of the body. McNamara (2001) supported similar results in her ethnographic study of terminally ill patients in both inpatient and outpatient settings.

Patient interaction with the family over time hinted to clues of the progress of illness, often irrelevant to the verbal reassurance, hence this shows that non verbal interaction can be equally powerful; and that consciousness of reality is also constructed by interpersonal exchanges. Indeed, patients developed awareness of the progress of illness through the subtle changes of their families' behaviour. For example, they picked up on families' tension when trying to convince them for new or better treatment; intensified efforts meant that something was going wrong. Patients' observation of family worrying faces after meeting with the doctors initiated queries. Carers coming back from the meetings with doctors 'with *red eyes*', was picked up by at least 3 patients over time. McKechnie et al. (2007) confirms these findings with the case of a patient who said in an interview that family visited her '*with the look of death in their eyes*' (page 261).

Another ethnographic study which followed terminally ill patients in Canada over their last few months of their life, described how patients became extra vigilant of the families' reactions near the end of life Staton et al. (2001). These findings also confirm the clinical observations of Kelley & Callanan (1992) in a hospice setting and suggested that clinicians should look for non verbal signs of communicating awareness

Yet, patients did not communicate their awareness openly most of the times, which in turn can bring challenges to others who wish to assess patient understanding. The findings of this study propose a new area that can indirectly suggest that patients pass through to different stages and it is related to illness progression. Having the benefit of following patients over time, allowed the capture of change/ shift of patients' mindset over time and of their priorities. The following section elaborates on this concept.

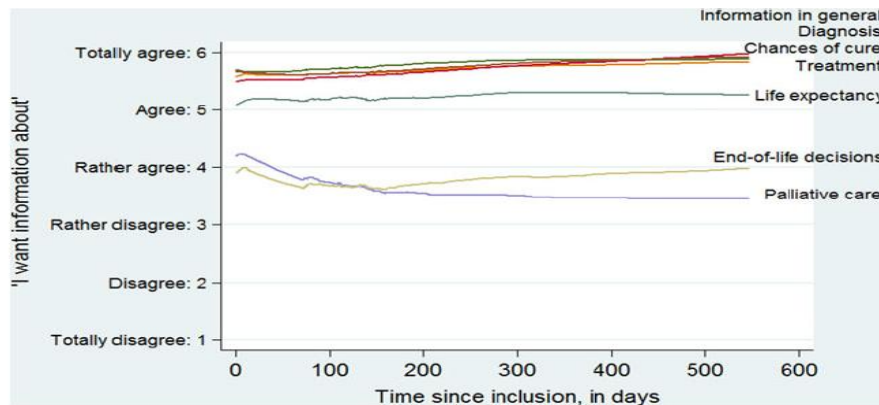
10.5.2 Orientation over time

There are two important issues addressed in this framework: phases are not defined by clinical stages (for example see doctors' perspectives, Chapter 7 Section 7.3.1) but instead by the patient experience of deterioration. Secondly, it emphasise the importance of time,

as patient experience follows the illness progress over time, underling emphatically the importance of longitudinal explorations in palliative care. Three broad phases were identified in this process, as expressed by patients; not getting better, getting worse, and dying. The time between not getting better- getting worse, shares some similarities with the living dying interval theories of dying: living- dying interval (Glaser & Strauss 1968); and clinical phases of chronic living- dying phase (Pattison 1977). Although these stages were defined as the time between the points of acknowledging the possibility of death to death, we propose that particularly for patients who are not aware of their prognosis, these stages relate more with the experience of deterioration and only much later with the knowledge of the possibility of dying.

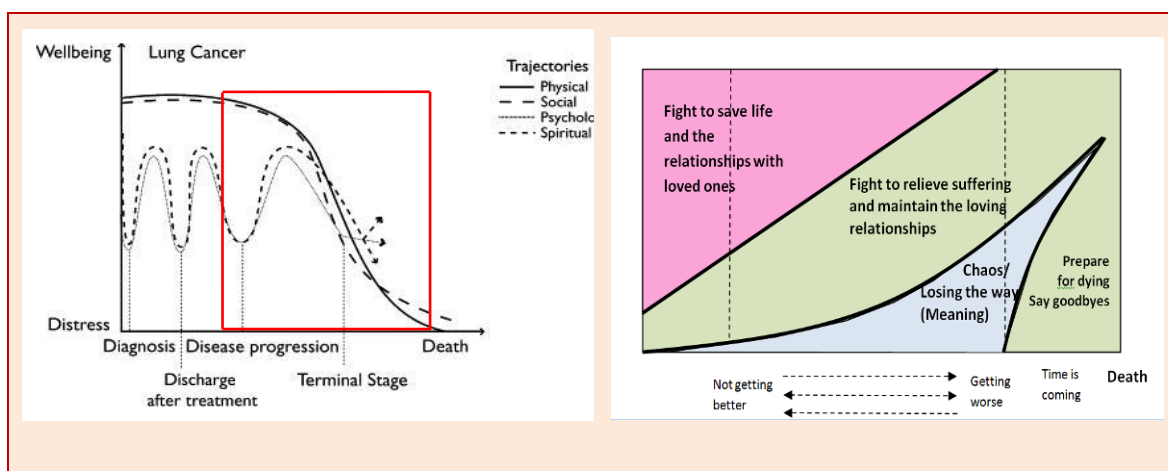
In an effort to understand patient's trajectory, Pardon et al (2012b) attempted to investigate information preferences (diagnosis, prognosis, treatment option, and palliative care and EoL decisions) of patients diagnosed with advanced lung cancer over time. However, they found that patients overall did not change much towards wanting more or less information about diagnosis, prognosis, and treatment options; a small variation only of preferences for information about palliative care and ELDs was found (Figure 10-2). According to this study, the information that patient might wish to have in terms of diagnosis, prognosis and EoL care, did not show any significant change in patient preferences eventually. Similarly, the patients -participants of the current study, did not ask a lot of information regarding end of life decision overtime; yet their preferences or priorities changed; perhaps a sole focus on information wishes might not be sensitive enough to suggest priorities' change. Thus, this study focused on exploring goals and preferences throughout the patients' trajectory, directly from the patients' perspective.

Figure 10-2: Information preferences of the studied patients over time (Adapted from Pardon et al 2012b, p. 2478)



The findings of this study zoom into the last period of the trajectory, as mapped by other researchers. It explores what happens in the fairly steady line period suggested in illness trajectory of cancer, until the rapid decline (Lunney et al. 2003; Lynn & Adamson 2003). Indeed, the patient trajectory proposed by this study, looks at a focused period of the cancer trajectory and explores in greater depth the time period from the disease progression point to the death point, as proposed by Murray's team within the psychosocial trajectories in cancer (Figure 10-3) (Murray et al. 2007). And as shown in the figure above, the angle of this study approach does not rely on patient's well being- with assessment criteria proposed by others external to patient- , but on patient's concerns and focus over time. This framework thus, suggests more of an experience trajectory rather than a medical trajectory and it shifts us right from the biomedical and takes us right into the patient and family experience. This is very important, given that patient satisfaction and quality of life has been argued depend on the interaction between patient experience and of expectations/goals and on the extent to which these expectations are met over time (Carr et al. 2001). Such an approach brings new insights into individual patients' quality of life, and can raise important implications for provision of patient centred care (Carr & Higginson 2001).

Figure 10-3: Trajectory of psychosocial wellbeing (adapted from Murray et al. 2007, p.397) and trajectory of orientation of priorities by this study



The main focus of this framework is on the priorities/goals over time, and patients' shift of mind orientation until death. Although it could be argued that this describes also decision-making, for patients in particular the term orientation was considered more appropriate, because patients' orientation did not lead to/translated into decision making at all times, with the exception of the final stage of dying; and again not for all aspects.

The term orientation was chosen in this model to describe the changed focus over time for an additional reason; this model does not suggest that these preferences and goals have an absolute value; that the specific goals or preferences are the only aspect of concern in patients' mind. Instead, the findings of this study showed that the weight of those values was re-appraised in response to life circumstances (i.e. health deterioration, the impossibility of the wish, family circumstances, fatigue from the illness itself, realisation of dying, etc.) and not necessarily the values themselves. Effectively, this means that whilst preferences and concerns might not have changed over time, their importance changed, and hence their priority during a particular phase of the patient trajectory. For example, when Giorgos realised that he was getting worse and not better, his priority became to save his marriage. This did not mean that he no longer wanted to fight for his life and was

not interested in possible new treatments, but at that point the former became the most important concern. Effectively, whilst he deteriorated and became more breathless, he claimed to have a more fulfilling life, because he had restored his relationship with his wife.

The above findings correlate with the arguments offered by the field of transition research. Transition has been defined as the inner reorientation and self-redefinition that people go through in order to incorporate change into their life (Bridges 2004). Research into chronic illness has looked extensively on patients' transition into their illness trajectories and described transition as the process of incorporating the change or disruption into patients' lives. (Shaul 1997 (rheumatoid arthritis), Rossen 1998 (elderly-relocation), Fraser 1999 (stroke), Hilton 2002 (stroke), Martin-McDonald & Biernoff 2002 (dialysis), Kralik et al. 2003(multiple sclerosis)).

In this study, awareness of illness progress and experience of deterioration were shown to be instrumental factors in changing priorities. The importance of awareness was also underlined by Meleis (2000) who supported that transition from one state to another can only occur if the person is aware of the changes that are taking place. Then this awareness is followed by engagement, where the person undertakes activities such as identifying new ways of living and being, modifying meanings and former activities (Kralik et al. 2006).

The findings related to patient orientation over time, revealed that the more patients realised that cure was not certain and that they were getting worse, the more they shifted their focus onto the relationship with their loved ones and directed their energy in securing their roles within the family. Moreover, patients' preference to relieve their suffering gradually took priority over treatment as their condition deteriorated and the symptom burden increased. Near the end, when they became aware of their imminent

death, they actively fought to secure space and time for preparing to die and performed dying rituals, some of which necessitate families' participation.

Although most of the components of the patient trajectory were verified by all patients-participants of this study, it should be mentioned that the length of each stage was different for different patients and patient journey did not follow a linear progress. Patients fluctuated between phases. There was a period of uncertainty marked with fluctuation, and continuous change; this is similar to what Parkes et al. (1988) argues in his work on psychosocial transition in bereavement. Parkes described those periods as a bargaining phase between stages. Transition signs come and go until they become consistent. He argues that bargaining behaviours often include anger and despair and continuous change. When patients of this study adopted such behaviours they were often misinterpreted as not knowing what they want and therefore not being reliable by their doctors. But actually these behaviours could be a sign of a transition process from one stage to another, which health care professionals could consider when looking to forecast an approaching change within the patient trajectory.

The shift in priorities, the re-evaluation of meaning (e.g. Giorgos case: from securing life to restoring marital relationship), and the focus on different activities (from adhering to treatment in order to survive to refocus on securing roles within the family) might be signs of the patient moving from one stage to another in the trajectory. The understanding of such signs could alert health care professionals about a potential upcoming change and consequently assist them with re-assessing and adapting care plans accordingly. Murray et al (2007) and Murtagh et al (2008) have raised the need for identifying predictors which could enable professionals understanding of where patients are in their journey. This framework of patient orientation/ focus over time, might offer an alternative way of identifying patients' priorities as a way of understanding where they are in their journey.

The question remains though, what triggered transition from one stage to another? Were there any critical events that activated this process? Some triggers, such as awareness of a new metastasis; medical choice for a new colostomy which the patient refused; the death of a fellow patient with the same diagnosis; repeated crisis uncontrolled dyspnoea; the diagnosis of cancer of the main carer seem to become the turning points for patients to move on to the next stage. The triggers of a transition actually were triggers of acquiring awareness of situation. The various studies involving multiple transitions provide evidence that most transition experiences involve critical turning points or events, which are often associated with increasing awareness of change or difference or more active engagement in dealing with the transition experience (Shaul 1997; Rossen 1998; Fraser 1999; Hilton 2002; Kralik et al. 2003). This is an area that palliative care research should focus on in the future, in order to enhance our professionals' ability for a more accurate prognosis, but also for better planning and provision of appropriate care according to the trajectory stage.

10.5.3 Relationship with their family

The patient data collected over time showed that as patients were losing bodily independency gradually, they focused more on their roles within the family. Perhaps, the maintenance of social roles gave them a sense of control, in contrast with the gradual loss of functional autonomy over time. These results seem to contradict the results of other studies. The importance of the bodily function to patients' identity was addressed by Lawton (2000). The author's exemplar ethnographic work on dying patients in a UK hospice, underlined the importance of bodily function in maintaining identity, arguing for an embodied social death, where the selfhood diminishes when the body's capacities and attributes shrink. Similarly, Murray et al supported that the physical decline is followed by social and psychological decline. Yet it would have been helpful if the later authors explained how they defined and measured patients' psycho-social wellbeing and how they assessed its change (Murray et al 2007; See Figure 10-3). On the other hand a few other

studies seem to support the strengthening of relationships despite the body deterioration. Vachon (2010) argues that patients would like to manage their impact on family, whilst Volker (2005) in a interview study regarding patient perspective on EoLcare, found that participants gave great importance in strengthening relationships with their loved ones and relieving their burden near the end. Future research could perhaps explore further the psycho-social trajectories, revealing the parameters that influence the reasons behind either psycho-social decline or not.

Family data confirm the trend of an increased focus on the social roles within the family, whilst the bodily roles deteriorated. Families did not deprive patients from their prior roles when addressing family matters despite the loss of patient's bodily function. Even in advanced stages of the illness progress, families did include patients in discussions about family issues, such as children problems, relatives' matters and family planning, respecting their opinion and advice. It could be that because patients belonged within their family, their personhood did not diminish, despite the body deterioration. These findings might offer an alternative explanation in relation to personhood preservation. It might be that personhood is lived differently in the Greek culture.

10.5.4 Imminent dying

Limited attention has been given to the deathbed scene itself in which the dying person, family, and caregivers are provided with their last opportunities for direct interaction (Corr et al 1999). This study offers a unique view onto the dying phase, as I followed patients until death.

A possible sign which could hint at the forthcoming phase of imminent death was withdrawing; meaning not being interested in the treatment regimens and blood test results; in contrast to their eagerness to be updated during prior weeks. All dying patients seemed to drift slowly between two worlds. Indeed Internal space and time seem to increase its importance near death. Maybe patients were selective to those things that

were important to them, as their energy levels were not enough to deal with all circumstances. Lawton (2000) and Copp (1998) and McKechnie et al (2007) identified this aspect of withdrawal and described it under social death.

After the signs of initial withdrawing, patients' behaviour changed rapidly over the last two weeks of their lives. They all became very active and expressed their requests directly and persistently. This change challenges the assumption that dying is a passive phase, where patients gradually withdraw. Contrary to this notion, most patients were actively engaged in the preparation of their dying. They undertook specific actions towards preparing for the 'journey' as most of them described it and communicated symbolically.

Dying messages during last week of life fell into two categories: descriptions of what dying patients were experiencing and requests for what the dying needed for an appropriate death. Specifically, at least half of the patients said that they had visits from deceased members of their family and friends, and said that they spent their nights having long talks with them. Sotos and Tamara in particular, described visits of their parents or deceased community members and suggested that they had come to prepare them for the journey which would start soon. Some patients invited family and friends into the hospital or asked to speak to them on the phone, whilst they had been avoiding them before (Sotos, Con, Natasha, Sila, Fritos). Those who wish to die at home, during last week of life they persistently asked to return home (Pablo, Sotos, Tamara, Ursula, and Fritos).

Kelley and Callanan (1992) when describing the "nearing death awareness" they identified expressions of final requests. The findings of this study revealed specific requests expressed hours before death, consistent across patient groups based on the cultural tradition they followed – as explained in Chapter 2. Requests related to preparation of the journey for after life including specific clothes and shoes ; requests for the favourite taste or smell to take along in the journey, expressed a few days before death; a ritual of farewell with blessings and advices for the future given to children by patients- parents,

some hours before death. In the case of Sotos -who came from a rural area which performs ancient Greek customs until nowadays - a very specific ritual was performed a day before death, involving lamentations found in ancient Greek tragedies; this ritual was initiated by the patient himself, and understood by the immediate family only. For patients attached to the Greek orthodox religion, receiving Holy Communion and confession, initiated the final act of dying. (Chapter 9, Table 9-1)

Greek culture evidences a wealth of rituals in all aspects of life with a special focus on dying, as presented in the second chapter of the thesis (section 2.2). The findings of this study confirm that Greeks still employ them when they are dying. The importance of rituals is not only that it is a manual for preparation, but also offers the codes for communicating dying without having to verbalise it. It is a safe place to express feelings without having to directly talk about death (York 2000). It offers a comfort space for all to exist and deal with it, by employing symbolic actions not words. Rituals are important in allowing the release of the tension and the express of the loss and grief, in the safe environment of symbolism (Leming & Dickinson 2010). We should therefore learn to recognise them and facilitate their actualisation when patients and families initiate them.

Symbolic statements about preparing for travel or speaking with someone long since dead or specific requests attached to specific cultures can be considered as triggers of the final stage before death (Spall et al. 2001). Although such communications were frequently dismissed as empty or enigmatic expressions of confusion, they may actually offer the possibility of arrangement for the place of death in time and also of meaningful conversation at the end of life and opportunities to finish remaining business, thereby allowing a sense of closure to both dying persons and their family.

10.6 Clinical implications

10.6.1 Late transition to palliative care- and holistic care not practiced

It is clear from the findings that patients were offered limited time and space for transition to palliative care, as care provision was dominated by the focus on cure until the very advanced stages of the disease (Chapter 7). This resulted into a compact dying experience with only some days left for the dying preparation (Chapter 9). Some possible reasons for the late transition to palliative care were identified to be the doctors' perception of their role of defeating cancer and prolonging life at any cost; the lack of communication of disease progression and prognosis to the patients and the belief that patients do not want to know the truth; the view that there is not such a thing as a 'good death' and the lack of training in palliative care and symptom control.

However, the findings suggest that all patients developed awareness of their prognosis, although communicated during the last 2-7 days before death, which inevitably meant that there was not always enough time or the right circumstances for the dying preparation to take place (Chapter 9). The findings showed that awareness of prognosis enabled patients to sort out unfinished business (Pablo), enjoy the final part of life as they wished (John), support the choices of the wife as a final gift to her (Giorgos), offer their last guidance and blessings to the rest of the family (Sila and Sotos) and prepare themselves spiritually and physically for the big journey (Tamara, Sotos and Sila) (Chapter 8 & 9). Families said that awareness of dying in time would have guided them in supporting patients' last wishes and choices, rather than focusing on administrative tasks and concerns of treatment compliance; instead of spending all their energy with managing the system and its bureaucracy, they would rather invest in the last valuable moments they could share with the dying patients (Chapter 8).

Not only in Greece but also in other European countries health care professionals are reluctant to talk about the terminal prognosis (Millar et al. 2013). There is an ongoing

controversial debate regarding the beneficence of telling truth in non-American or non-UK culture. Disclosing prognosis is considered as not serving the best interests of terminally ill patients in Southern and eastern European countries (de Penthény et al. 2011; Kazdaglis et al. 2010), including Greece (Mystakidou et al. 1996). However, Anne-Mei The (2003) discovered in an ethnographic study about communication in the Netherlands, that even in a health care culture of western Europe, where individual autonomy and open communication is supported, doctors have developed strategies for not disclosing prognosis, despite the common notion that they do. This is particularly evidenced in hospital settings (Hancock et al. 2007). This means that we might have overestimated the move towards open communication of prognosis to the overall dying population, given that, the bulk of care and decision making at the end of life are delivered in general hospital, primary care, and aged care settings most patients will die in the hospital (Cohen et al. 2010).

The above findings highlight the need for transition to palliative care and the dying phase earlier (or corresponding to patient readiness to move on), and the need for improving communication, particularly with regards to prognosis.

Recommendation for education

- a. Training in communication and particularly in breaking bad news: Doctors said they lacked confidence in breaking bad news, and they would value training in doing so. Short training interventions to enhance communication skills have been shown to have a positive effect in other settings (Goelz et al. 2011).
- b. Training in palliative care: health care professionals should be introduced to holistic care and be exposed to the importance of quality of care. Patients progressively prioritised the management of side effects and symptom control over treatment because quality of life became more important than cure.

Awareness of the reality of dying raised issues that are important values in life, highlighting the importance of the spiritual care

The health care system should impose a solid educational programme to all levels of academic education in order to enable future health care professionals to give emphasis on holistic care- the very nature of palliative care- and enable them confidently to share decision making whilst exploring the best options for their patients and their families. Such programmes had shown to effect students and professionals' performance. A pre-clinical educational programme in Taiwan- a country where palliative care was only recently established- seems to have improved the competence of future clinicians in dealing with End of Life care decisions and compassionate care (Shih et al. 2013). According to their evaluation, the programme was positively related to improvement in "truth telling is helpful to a good death." In addition, improvement in the perception of "compassionate care" was correlated with higher improvement in discharge planning and home care.

Although it is assumed that education and training need attention in countries with no established palliative care, surprisingly, the undergraduate training in palliative care seems to pose challenges for the UK nurses even nowadays (Becker 2013). He reports that of the 34 practice competences that all nursing programmes in the UK need to adhere to since 2011, Palliative care is only briefly mentioned (Nursing and Midwifery Council (NMC, 2010a). And in the ten standards that provide the theoretical framework within which programmes are delivered, end-of-life care is mentioned only once (NMC, 2010b). Even more, employers are only funding staff for individual modules that they perceive to have a direct relevance to clinical practice. The resultant dearth in full graduates is just beginning to emerge. This highlights the need for education programmes establishment at the national level and national policies to support professionals training.

Clinical training in palliative care should be incorporated into the ongoing educational development of all clinicians in order to update knowledge, enable professional support and space of development, empowerment, and improvement of existing practice. A recent US national survey of oncology fellows which assessed their knowledge and competence in palliative care conducted in the US indicate that palliative care education has penetrated US oncology fellows' training, but substantial deficiencies remain in all the core palliative care education domains: communication skills, symptom management, and psychosocial care (Buss et al. 2011). This highlights the importance of ongoing training within clinical practice. Charalambous & Silbermann (2012) highlight the importance of clinically based palliative care training for oncologists, arguing that the inadequate pain management is due to an imbalance in the care provided to patients, focusing predominantly on disease-directed therapy and neglecting to address physical, psychological, social, and spiritual consequences of disease and its treatment. They also highlight the limited effectiveness of the existing educational methods in both undergraduate and postgraduate curricula. They recommend therefore, that training should rely both in theoretical knowledge and ongoing clinical support under supervision and guidance by experienced professionals in palliative care.

Given the experience of clinical training reported in other settings, education of palliative care, based in the hospital setting, could improve the skills and communication of professionals within the setting. Perhaps the teaching of palliative care in each unit, and keeping the scale small and within the teams at first, would not interfere with the routines and structures of the professionals' busy schedule. Also training within the team might enable supportive relationships and better links of communication to be established (Weaver et al. 2010). Within these meetings, beneficence tension could be discussed and allow professionals to explore it within their own circumstances. If they realise that most of their tension is related to everyone's good intentions and not between competing ethical principles, maybe the defensive barriers will be diminished. Clark (2010) suggests

that helping professionals develop awareness of beneficence as desired outcome helps safeguard the inclination to prematurely judge the behaviour of other colleagues. Acknowledging this assumption verbally can be especially helpful. In this training the hospital could utilise the educational people of the existing services.

I would recommend multi-professional education as training to a multidisciplinary audience has been found to give the opportunity for clinicians to gain awareness and appreciation for the skills and roles of disciplines other than their own (Mason et al. 2002). Educational approaches of this type can be effective in the context of delivering palliative care education. A short multidisciplinary education program focusing on the core elements of palliative care was developed and delivered in both metropolitan and regional areas of Australia incorporating a range of disciplines and care settings. The implementation of this program was assessed to improve significantly participants' ability to identify patients likely to benefit from a palliative approach, their communication skills, symptom management, family-centred care, legal and ethical issues, and grief and bereavement (Quinn et al. 2008).

Nevertheless, it might be challenging to establish such a program in the short term. As hierarchy is so strong, teaching all professionals together might bring relational challenges and thus may not be effective. Maybe hierarchy should be respected at the time. An alternative way towards better understanding and acceptance of the different professional groups could be bringing in a respected nurse to teach the doctors and a respected doctor to teach the nurses. In addition, family members could be invited to talk about their experience with the dying patient. Perhaps this is the first step to encourage multi-disciplinary action and team work. The areas recommended to be covered based on the study findings and the gaps identified in care are:

- a. Symptom control not only treatment choices
- b. Psychosocial care- communication skills

- c. Somebody from the local community , what can be done at home
- d. Family members of prior patients to share their experience and their views-
their suggestions
- e. Practical support for families

Recommendation for clinical practice:

For the care of patient

1. Assess stage of patients' awareness of the illness progress and of prognosis and direct care planning according to those signs.

"Patients with poor understanding of prognosis are less likely to discuss care preferences with family members, suggesting the importance of provider communication with patients regarding prognosis." (Wagner et al. 2010, page 527)

This understanding has practical significance for health professionals planning interventions to help individuals with advanced cancer live out their lives in ways that are meaningful to them. The assumption here is that understanding of prognosis is acquired by the specific information given with regards to prognosis. But disclosing information might not be the only way of reaching this goal. This is very important, given that we found that not all patients wanted to discuss this issue, albeit they were suspecting or knew the truth.

The findings of this study can recommend another way of approaching patient awareness, based on their experience of their situation over time. The framework of longitudinal experiences and orientation might be helpful to clinicians in terms of understanding patients' awareness over time. It might offer insights as to at what point the patient is in terms of their awareness of the journey. Thus, clinicians can respond to patients and families' orientation rather than imposing their own thinking and therefore offer the relevant kinds of information at that specific point in time. Hence, this could prove to be a

useful tool, particularly in countries where open communication about illness progress and prognosis are not widely practiced.

The framework of orientation/ decision-making over time might be also very useful in delivering appropriate care, as it may offer an understanding of the stage the patients are in their trajectory. By identifying the patients' main orientation is in terms of main goals and priorities, clinicians might be able to change gear in the care provision, to meet the patients' needs at different time points (see more in section 10.5.2). Indeed, the understanding of the signs of patients' orientation over time, could help professionals direct care towards introducing palliative care and dying care appropriately and at the right time.

Clinicians of a palliative care team in the UK who used this framework, reported back, saying that they found it very useful in terms of understanding patients' own view of where they are in their journey. They confirmed that information does not necessarily develop awareness. Also, the fact that patients come again to the next clinical appointment with the same issues, is often interpreted as patients' denial. But it actually can be that patients and families have a different orientation from the health care professionals, and thus insist on the same matters. Hence, clinicians suggested that this framework challenged their thinking and gave them some guidance/ a map to shift their thinking towards assessing through the patients' own experience.

2. Psycho-social-spiritual aspects of care should be encouraged to be assessed routinely, so that health care professionals will engage in practice with those aspects and assess their performance on those domains.

Assessment on a routine basis of psycho-social needs- using standardised measures, can improve holistic care in medical oncology clinics (Alsaleh 2013). The POS is a short multidimensional measure that may be used in practice to address the holistic nature of care (Hearn et al. 1999). If used routinely, it can enable professionals to measure patient

outcomes, and make sure they address the psychosocial aspects and subsequently be able to evaluate and properly act on the domains that they have not done well on. Currently, I am involved in the translation and validation of I-POS into Greek in collaboration with a home care team in Athens.

3. I would recommend a folder with resources provided by exemplar clinical services for support and would encourage the link between teams so that they can support each other. At the moment, a link between the oncology hospital under study and a recent home care team is in the process of establishment so that they can enable a smooth passage of patients to their home.. Also, with the help of MacMillan, I have provided these two services with relevant material in support of their practice. They are in the process of translating some of the material into Greek.

For the support of the health care professionals:

The study findings showed that both nurses and doctors expressed feelings of vulnerability and difficulty in accepting each other. On the one hand they must be the experts, but on the other hand they need to accept the expertise of the other groups and being challenged for their choices. A case where team meetings can be facilitated once a week might enhance teamwork and support for each other. A local facilitator, who they trust within their organisation, may facilitate the group discussions- bring in the things that are important to professionals as well (Van Staa et al. 2000).

A supportive ward environment might provide the safety and space for nurses to explore their roles and abilities in providing best care for patients, but also give them the strength to ask for support when they need it. Tay et al. (2011) found that nurses who were task-orientated, who feared death and who had low self-awareness of their own verbal behaviours inhibited communication. A supportive ward environment increased and facilitated communication in nurses, whereas conflict among the staff led to the increased use of blocking behaviours (Tay et al. 2011). For nurses in particular who wanted to

have a more active role in patient care, they could focus on the end of life care, an area that physicians were most reluctant to get involved. A literature review on nurses' role next to the patient, has reported that nurses can be more active in the end-of-life decision making and more effective in meeting patients' needs, than other health care professionals due to their proximity to both patient and family (Erickson 2013).

10.6.2 Different focus of patients/ families, and professionals over time

It is clear from the findings, that patients, families and professionals had different focus, different priorities and goals over time. This led to tension between the different groups, difficulty in communication and challenges in the decision making and care planning. As discussed earlier (Section 10.3.2), the longitudinal data revealed that the decisions made about care overtime, reflected changes in preferences and choices of doctors, families and patients. Although palliative care research has identified some of these aspects and factors influencing changes over time, it has not looked at their interplay and has not yet explained how these shift over time (Kirk et al 2004; Curtis et al 2008). The prospective longitudinal nature of this study revealed some possible patterns of mindset shift which grew differently across patients; families and doctors (See more in Section 10.3.2).

A number of implications might derive from the interplay of longitudinal perspectives of the different groups. We may not necessarily want to merge these different perspectives together, because everybody has different experiences, from time to time. However, the knowledge of each group having a different experience/ priorities, perspective can be very empowering. The awareness of the different views might help reduce the beneficence tension which is often found between the different encounters. For example, the clinician would be able to say 'I am thinking of something different. What you do you think about this?' as opposed to if we all thought together there would not be any problems.

The longitudinal figures (Figure 10-1) of orientation overtime can be used as a map to explore the different roles all sides take and who takes the lead each time over time.

Actually having this kind of understanding of the complexity and changeability of the situation, may enable health care professionals to understand where the families and patients are and where they might reasonably expect them to move to over time, as well as the patient and can guide decision making.

Families views and position is very important, not only because of their mediating role between doctors and patients, but because they also see the signs of change first. They are the ones who assess patients' well being and are vigilant to patients' wishes. Families notice the changes first and they are the first to attune with the patient change, by shifting their focus towards patients' preferences. Families could help the health care professionals to identify transitional points and flag up the possible changes in patients' orientation and illness trajectory. Families might not be always reliable in addressing patients' wishes and preferences (Dionne-Odom & Bakitas 2012; Epstein et al. 1989) but perhaps they can be most helpful in establishing the changes with the patient. Therefore, health care professionals could consult families for any possible changes in the orientation and goals of the patient that might instigate transitory points, and utilise this information to assess a possible shift to the next stage of the trajectory. This study can make some suggestions in terms of those signs in patients' behaviour that might signify transition (Table 10-4); albeit it acknowledges that patients in different cultures and contexts might give different signs. Nonetheless, it suggests that such signs exist and therefore health care professionals should be aware of this detail and try to recognise them with the help of the family.

Table 10-4: Signs of transition to different awareness stages of illness

Getting worse
Anger and depression usually expressed during transition period between stages
Change in preferences and wishes for care
Willingness to participate in updates , care options or withdrawing interest over them
Changes of the focus of patients' discussion and main concerns – patient focus moving from illness to family issues and engaging more with familiar social roles
Sudden preference to meet with people who have not seen for a long time
Persistent request to go home or visit their homeland
Time of death approaches
Describe visits from deceased members of the family, usually in their dreams
Invite broader family into the hospital during the last few days to initiate farewells
Seek actively to advise and guide family members for future actions
In contrast with prior period, less interest for symptom relief
Specific requests for favourite taste and smell and special clothes for the journey
Requests for confession and the holy communion of the religious patients
Specific rituals related to local cultures, often understood only by the family (e.g. symbolic songs of migration, laments)

Decision-making about curative treatment and palliative care

It seems that nobody really wants to give up on the prize of 'cure might be possible'. And that is perhaps one of the reasons they are all so negative to palliative care, as it is associated with accepting death and dying. Yet, the conflict between the groups might not relate to stopping treatment; perhaps it refers to the aggressiveness with which active treatment is decided. This is something that could be negotiated between the groups. Within the negotiation of the aggressiveness of treatment, clinicians could suggest continuation of treatment, but introduce palliative care to address the rest; symptoms, side effects, psycho-social needs. Hence, decision making over aspects of treatment may

not contradict decisions over palliative care. Instead they could be offered together. This preference was identified in a study of patients with advanced cancer, where patients did not wish to move from the oncology service to palliative care service, rather than receive the combination of both (Back et al. 2009). Similarly, the patients and families of this study might have wanted to keep on the same route but manage it a bit better. Perhaps a possible pathway could be continuation of treatment despite deterioration, but have the side effects treated more vigorously, and at the same time have more space to prepare for dying when the moment comes.

10.6.3 The centrality of family in care provision and decision making

The findings of the study showed clearly that family has a central role in care provision and decision making. Yet, family's position as caregiver was ambiguous and heavily relied on the individual families' characteristic and abilities in caregiving. Professionals' controversial perceptions of family being both a supporter and a barrier resulted in challenges with communication and collaboration. This highlights the need for a better understanding of the family's point of view, of their ways of function and involvement in patient care and of their needs of support.

Family involvement in decision making

Health care professionals should start considering the family not as one person, but rather as a system with its own function and rules of operations. Some possible guidelines to help care professionals when approaching families with regards to caregiving and decision-making are presented in the table below (Table 10-5):

Table 10-5: Guidelines to approach families about end of life decision-making and caregiving

1. Observe family dynamics (need nurse and social worker involvement).	Look for two main areas of function: caregiving and decision making. Identify which family members are allocated to each locus.
2. Use a sociogram	Sociogram in comparison to genograms can help you explore family dynamics; it might help you identify the dominant and supportive roles, as well the stronger links between family members and patients
3. Ask patients which family member's preference and opinion they value most	This will usually refer you to the main decision maker.
4. Look for the dominant member- the one at the top of family hierarchy ; and then decide to have an individual talk with the key person first	Most often, this person will be the decision-maker. Direct information and issues re decision making to this person.
5. Look for the person who is mostly next to the patient	Most likely this person is in charge of caregiving. Refer to this person for the appropriate issues, and concerns.
6. Check frequently if a family conference is needed (with or without patients)	During transition points, families need support in order to re-define their roles and adapt to new functioning
7. Never assume that the person next to the patient is the decision-maker. Always check	Quite often we make the assumption that the person who is usually next to the patient is the responsible for the care decisions.
8. Look to support the significant roles within the family dynamics	These roles are important to maintain stability in the family over time, particularly during crisis and transitions

Family support

Increasingly, the importance of the role of the family and their input in patient care is getting recognised (Payne et al. 2010; Andershed 2006). The instrumental role of the family in enabling home death has been recognised (Grande & Ewing 2008). The findings of this study confirmed a similar reality for Greece. The majority of the patients preferred to die at home, but they did not with the exception of one. One of the factors that prevented home death was found to be the lack of family's confidence in dealing with dying at home alone. Given that at this moment there are no home care services in Greece (with a few exceptions, see more in Introduction, Section 1.3) families would need to take

full responsibility for patient support around death. Most of the families found this possibility overwhelming albeit they wanted to support patients' preference for dying at home. However, if appropriate support and training was given to the family, they would be empowered to support their loved ones at home.

As observed in the hospital setting, nurses of the ward offered informal training to families, in order to secure family's hands-on-care. Families welcomed this attitude and felt that it helped them actualise their duty of caregiving. Families were proven to be open to learn and provide for the patient. Hence, we could build upon this informal procedure and introduce some practical training for the families.

Also, families expressed lack of confidence in dealing with the uncertainty of the dying process. They recommended that if they had been prepared for what to expect and how to react/ support, they would feel more confident in keeping the patient at home. Some training and back up communication for symptom control was perceived to be most helpful in order to take such responsibility. If we invested in training the family, and tailoring support according to their strengths and weakness, they would be more supportive in enabling patient to live to their end and die at their preferred place.

Acknowledging their role as collaborators would recognise their role of advocacy for the patient, and increase family's satisfaction of their performance. For the families, the most frustrating thing was the structural barriers, and bureaucratic services. Families wanted to be with their relatives and maximise the time they have with them. By doing all these administration, organisation of care, they did not have enough time next to their patient. Therefore, reduction of the administrative work for the families and of the length of time in dealing with the bureaucratic system would reduce the burden for the families and secure more quality time between families and patients.

Some recommendations to guide professionals when involving families in patient care, based on the family's figure of orientation and decision making (Table 10-6), follows:

Table 10-6: Families' preferences with involvement of care provision overtime

Fight to secure the loved ones (cure is possible)	Families can offer their help both caregiving and co-ordination of services. Most of the family is utilised for support. Fighting mode
Fight to keep the loved one longer (Cure is not certain)	Families are less keen to deal with administration, and more with co-ordination of care, as they feel this way they advocate for the patient and safeguard survival. Hands- on- care is allocated to the caregiving members.
Fight to fulfil the loved one's wishes (death is certain)	Families would want to completely focus on patient care, family relationships, fulfilling patient wishes, securing quality time with the patient. Not happy to spend time with administration and co-ordination of care. Hands- on- care is still welcomed

10.7 Implications for future research

This study demonstrated that the use of social constructionism in palliative care can be fruitful in terms of understanding how care is shaped over time and particularly how the interaction between patient/family, health professionals and system construct the trajectory of dying. Although mostly found in cultural research, it can be very valuable to palliative care research; it could become the framework to explore further how decision-making takes place amongst the involved encounters; how it is shaped and negotiated between all parties overtime.

This study followed patients until death and revealed two important aspects of the dying phase: dying is an active stage and patients lead it. The findings identified specific signs of symbolic communication and the employment of specific rituals in the process, which could be very valuable in diagnosing dying and therefore appropriating care (Ellershaw & Ward 2003). We need more studies to look at the dying phase and explore its manifestations and dying patients' needs, for different groups of dying patients, different diseases across different cultures. However, that requires training on behalf of the researchers to deal with this sensitive period skilfully and appropriately, whilst retaining their researcher role (Namei et al. 1993; Wilde 1992)

"If participants are sharing difficult emotional issues with the researcher, it may be impossible to remain unmoved and not to respond to what is being said (however tight the interview schedule) Indeed, many argue that there must be equality and reciprocity in the research relationship; we should not just collect the data and run. This again may become a part of the analysis rather than the pretence that one did not offer any kind of support or recognition of the difficulties of the research participants." (Plant 1996, page 340)

The study findings suggest a new framework of exploring longitudinal experience and decision making process overtime, by looking at participants' orientation as it shifts whilst awareness of illness progression develops. It is a fresh look at the notion of trajectory based on the orientation of priorities of participants through their own eyes overtime. Findings built upon the need identified in the literature of understanding the changes in needs and preferences of patients and families as they develop in response to emerging medical and non medical developments from their own perspective (Talman 2012).

This framework may be proved quite important not only because of its longitudinal nature but because it is also a prospective model. The illness and symptoms trajectories developed so far can be very useful, though most applied retrospectively (Constantini et al. 2005; Teno et al. 2001b). We need models that can actually be applied to patients care while they are still alive. This framework of orientation trajectory developed prospectively, might offer an alternative approach to predicting illness progression. Although strict predictions of the course cannot be made, as each patient has an individual course; yet the stages proposed, may provide a rough guidance to clinicians to identify at which stage the patient might be and therefore change gear and attune care to the ever changing patients' needs.

However, the understanding of the complexity and changeability of the process and the interplay of different actors involved needs further exploration. The decision making

process should be investigated deeper, whilst aiming at understanding power dynamics, and factors influencing all parties towards choosing over different and perhaps conflicting priorities. Additionally, we need to explore the different levels of autonomy and participation as it is observed that the different groups have different focus and exercise variable levels of power into their negotiations.

Pardon et al. (2012) explored prospectively the changing preferences for information and participation in decision making patients with advanced lung cancer, but they only looked at patients' perspective and did not explore the reasons for change and the influencing factors. This framework might prove valuable for palliative care, as attempts to shed light into the multi- perspectives of the interactional process of decision making between health care professionals, families and patients. Furthermore, it provides new insights into the interplay of illness awareness, disease progress, priorities and goals and decision-making as they evolve whilst patient deteriorates. However, the framework is at its initial stages, and it is not known if these diagrams are sufficient. This approach needs to be tested in order to develop and be refined further. Therefore, I would recommend testing this in a bigger cohort of patients, across illness trajectory. Also, in order to accept any transferability I would suggest testing it in different settings (hospital, community services) and context (urban, rural). Also, I would recommend focusing on identifying those signals or transition points, and triggers that initiate transition and explore how they make possible the shift from one state to another.

Expanding the study population to include patients with other diseases, might offer a more diverse population and some opportunities for comparison with other group of patients, such patients with chronic heart failure, stage 5 chronic kidney disease, COPD, (Granger et al. 2006; Murtagh et al. 2011). Further work is needed for the dying phase. The cultural relevance of this framework could be explored by testing it with other patients either cross-culturally.

Further research is required to explore the identified longitudinal family patterns of involvement into patient care. The study introduces a system approach into family engagement with the health care services in order to provide care for the ill member. The findings revealed some patterns of family function and two poles of organisation: caregiving and decision-making; however, future research needs to explore in more depth the family patterns of function and engagement with health care. Some questions to be explored further are:

- How prior families' systems and members personalities shape the patterns of function around patient care.
- Which of those patterns are helpful and therefore, how can we improve the experience for families and patients by working through, their patterns?

The findings also underlined the importance of the family in shaping the dying experience for the patient. Families proved to have a crucial part in the patient's experience of body deterioration, but also the maintenance of the social identity until the very end. Family Systems Theory could provide a valuable framework to guide research on families required to provide the best comprehensive palliative care (Mehta et al. 2009).

Finally, this was the first study on a Greek population of dying patients drawing from in depth interviews and participant observation. All the participants of the study declared that they have been helped by taking part in this study and insisted I stayed until the end, despite the recommendations of the ethics committees; they said they would experience abandonment if I had withdrawn earlier (See more in Chapter 5, Section 5.16.3). This suggests that Greek patients are ready to engage with such sensitive issues if handled properly and thus more research should be conducted looking at their own points of views, preferences and wishes.

11. Conclusion

The study showed that dying is not static; rather it is constructed and altered over time. It showed the all importance of the interplay between decision making, illness progression, awareness of dying, family dynamics and their change over time in shaping patient trajectory at the last months of life. The care provision focused on cure and not on care, the different roles in decision making by the different actors, the central role of the family within the family system and people's shift of mind set over time were some of the parameters shaping the trajectories of illness and experience for a group of patients with advanced cancer.

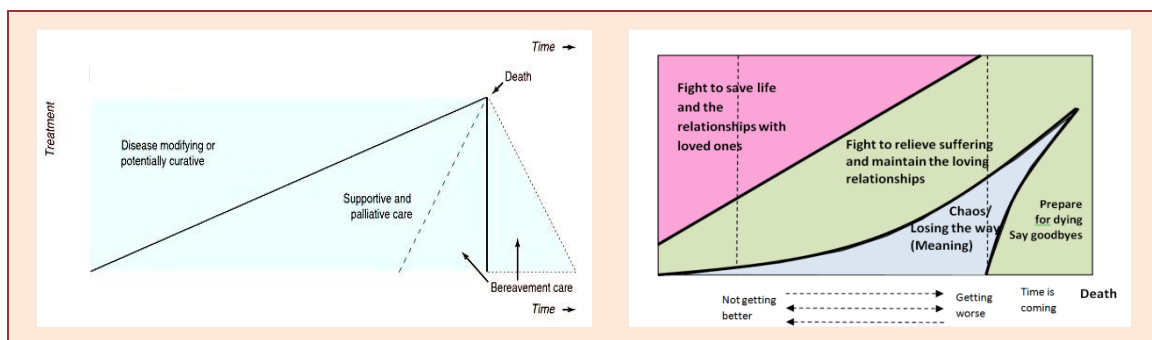
This study also unpacked processes of decision making and identified factors shaping its direction: the different focus of all participants involved over time, the change of the decision maker of the family and the different responsibilities on different levels that family members undertake were found to be the most important. It showed that decision making is therefore complex and is shaped by all actors involved (families- patients- doctors). The framework proposed to explain how decision-making happens and how it shifts and changes over time is a framework that could be useful in different contexts. It might be that the nature and relationship of different aspects will probably differ but, as a concept to study, it is really important.

Therefore End-of-life care is not just about the care, it is about the cultural norms and beliefs, it is about the family structures and systems and how they can operate within systems of care; and how people feel at that point in time, both physically, psychologically, socially. The relative importance of all those dimensions identified, might change depending on the culture, but all the dimensions I looked at that shaped dying and decision making, are relevant to all people. Even these dimensions might have a different level of importance; we actually ought to consider them when looking at death and dying.

Any theory- or decision making approach- which is not able to encompass all of that, is going to be inadequate, as a theory of dying.

The concept of mindset orientation of goals and priorities overtime may provide a new prospect for approaching trajectories in palliative care: It may provide a link between the palliative care pathway (Figure 11-1) and patients' own perspectives, preferences and goals and of their priorities overtime. It may suggest a way forward to address quality of palliative care over time, based on people's orientation and not only on symptoms or illness progression.

Figure 11-1: Patient orientation of preferences and priorities overtime as a new aspect for palliative care



(First figure Adapted from Lynn and Adamson, 2003)

Further exploration of the links between the trajectory of orientation and palliative care, would be most valuable in order to bring new insights into the quality of care at the end of life.

12. References

- Action against Cancer (2008) *National plan against cancer 2011-2015*, electronic source: http://www.anticancer.gov.gr/catalogue/SxedioDrasis_24selido.pdf [accessed January 2013]
- Aikman, P. J., Thiel, E. C., Martin, D. K. & Singer, P. A. (1999) Proxy, health, and personal care preferences: implications for end-of-life care. *Cambridge Quarterly of Healthcare Ethics*, **8**(2) 200-10.
- Alexopoulos, E. C., Koutsogiannou, P., Moratis, E., Mestousi, A. & Jelastopulu, E. (2011) Pain in cancer patients: The Greek experience. *European Journal of Oncology Nursing*, **15**(5), 442-6.
- Alsaleh, K. (2013) Routine administration of standardized questionnaires that assess aspects of patients' quality of life in medical oncology clinics: A systematic review. *Journal of the Egyptian National Cancer Institute*, **25**(2), 63-70.
- Altheide, D. & Johnson, M. (1998) Criteria for assessing interpretive validity in qualitative research in Denzin, N. & Lincoln, Y. (eds.) *Collecting and Interpreting Qualitative Material*. , London: Sage.
- Andershed, B. (2006) Relatives in end-of-life care--part 1: a systematic review of the literature the five last years, January 1999-February 2004. *Journal of Clinical Nursing*, **15**(9), 1158-69.
- Annunziata, M. A., Talamini, R., Tumolo, S., Rossi, C. & Monfardini, S. (1996) Physicians and death: comments and behaviour of 605 doctors in the north-east of Italy. *Supportive Care in Cancer*, **4**(5) 334-40.
- Aristotle (1998) *Metaphysics* translated with an introduction by H. Lawson-Tancred, Penguin
- Armstrong, T.L. & Swartzman, L.C. (2001) Cross-cultural differences in illness models and expectations for the health care provider-client/patient interaction. In Kazarian, S. S. and Evans, D. R. (eds.) *Handbook of Cultural Health Psychology* San Diego: Academic Press.
- Armstrong-Coster, A. (2004) *Living and Dying with Cancer*, Cambridge: Cambridge University Press.
- Aspinal, F., Addington-Hall, J., Hughes, R. & Higginson, I. J. (2003) Using satisfaction to measure the quality of palliative care: a review of the literature. *Journal of Advanced Nursing*, **42**(4) 324-39.
- Atkinson, P. (1992) *Understanding Ethnographic Texts*. , London: SAGE.
- Atkinson, P. (1995) *Medical Talk and Medical Work*, London: SAGE.
- Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (2001) *Handbook of Ethnography*. , London: Sage Publications.
- Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, **1**(3) 385-405.

-
- Atwal, A. & Caldwell, K. (2005) Do all health and social care professionals interact equally: a study of interactions in multidisciplinary teams in the United Kingdom. *Scandinavian Journal of Caring Sciences*, **19**(3), 268-73.
- Babinotis, G., (1999) *Dictionary of Modern Greek*, Athens: Lexicology centre
- Back, A.L., Young, J.P., McCown, E., Engelberg, R.A., Vig, E.K., Reinke, L.F., Wenrich, M.D., McGrath, B.B. & Curtis, J.R. (2009) Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: loss of continuity and lack of closure. *Archives of Internal Medicine*, **169**(5), 474-9
- Bates, M. S., Edwards, W. T. & Anderson, K. O. (1993) Ethnocultural influences on variation in chronic pain perception. *Pain*, **52**(1) 101-12.
- Becker, R. (2013) What future for palliative care education? *International Journal of Palliative Nursing*, **19**(3), 107-8.
- Bellou, V. (2007) Achieving long-term customer satisfaction through organizational culture: evidence from the health care sector. *Managing Service Quality*, **17**(5), 510-22.
- Bellou, V. (2008) Identifying organizational culture and subcultures within Greek public hospitals. *Journal of Health Organization and Management*, **22**(5), 496-509.
- Bellou, V. (2010) Organizational culture as a predictor of job satisfaction: the role of gender and age. *Career Development International*, **15**(1), 4-19.
- Blaxter, M. (1996) Criteria for the evaluation of qualitative research papers. *Medical Sociology News*, **22**(1), 68-71.
- Bloor. (2001) The ethnography of health and medicine, in Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds.) *Handbook of Ethnography*, London: Sage.
- Bloomer, M.J., Cross, W., Endacott, R., O'Connor, M. & Moss, C. (2012) Qualitative observation in a clinical setting: Challenges at end of life. *Nursing & Health Sciences*, **14**(1), 25-31.
- Bluebond-Langner, M. (1978) *The Private Worlds of Dying Children*, Princeton, NJ: Princeton University Press.
- Bottomley, A. (2002) The cancer patient and quality of life. *Oncologist*, **7**(2) 120-5.
- Bowling, A. (2004) *Research Methods in Health. Investigating Health and Health Services.*, Maidenhead: Open University Press
- Brewer, J. (2000) *Ethnography*, Buckingham: Open University Press
- Broom, A. & Kirby, E. (2012) The end of life and the family: hospice patients' views on dying as relational. *Sociology of Health and Illness*, **35**(4), 499-513.
- Bruera, E., Neumann, C. M., Mazzocato, C., Stiefel, F. & Sala, R. (2000) Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliative Medicine*, **14**(4) 287-98.
- Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., McIlwane, J., Hillary, K. & Gonzalez, J. (2007) Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care. *Journal of the American Geriatrics Society*, **55**(7) 993-1000.

-
- Bryman, A. (2004) *Understanding Research for Social Policy and Practice: Themes, Methods and Approaches*: The Policy Press.
- Buckman, R. (1993) Communication in palliative care: a practical guide. In Doyle, D., Hanks, G. W. C. and MacDonald, N. eds.) *Oxford Textbook of Palliative Medicine* Oxford: Oxford Medical Publications.
- Burns, C.M., Broom, D.H., Smith, W.T., Dear, K. & Craft, P.S. (2007) Fluctuating awareness of treatment goals among patients and their caregivers: a longitudinal study of a dynamic process. *Supportive Care in Cancer*, **15**(2), 187-96.
- Buss, M.K., Lessen, D.S., Sullivan, A.M., Von Roenn, J., Arnold, R.M. & Block, S.D. (2011) Hematology/oncology fellows' training in palliative care: results of a national survey. *Cancer*, **117**(18), 4304-11.
- Byock, I. R. (1999) Conceptual models and the outcomes of caring. *Journal of Pain and Symptom Management*, **17**(2) 83-92.
- Callahan. (1993) *The Troubled Dream of Life, Living with Mortality.*, New York: Simon & Schuster
- Carr, A.J., Gibson, B. & Robinson, P.G. (2001) Is quality of life determined by expectations or experience? *British Medical Journal*, **322**(7296), 1240-43.
- Carr, A. J. & Higginson, I. J. (2001) Are quality of life measures patient centred? *British Medical Journal*, **322**(7298) 1357-60.
- Carter, H., MacLeod, R., Brander, P. & McPherson, K. (2004) Living with a terminal illness: patients' priorities. *Journal of Advanced Nursing*, **45**(6) 611-20.
- Caruso, A., Di Francesco, B., Pugliese, P., Cinanni, V. & Corlito, A. (2000) Information and awareness of diagnosis and progression of cancer in adult and elderly cancer patients. *Tumori*, **86**(3) 199-203.
- Cassell, J. (2001) Ethical principles of conducting fieldwork, in Bryman, A. (ed.) *Ethnography*, London: Sage Publications.
- Centeno, C., Clark, D., Lynch, T., Racafort, J., Praill, D., De Lima, L., Greenwood, A., Flores, L. A., Brasch, S. & Giordano, A. (2007) Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force. *Palliative Medicine*, **21**(6) 463-71.
- Charalambous, H. & Silbermann, M. (2012) Clinically based palliative care training is needed urgently for all oncologists. *Journal of Clinical Oncology*, **30**(32), 4042-3.
- Cherny, N. I., Baselga, J., de Conno, F. & Radbruch, L. (2010) Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative. *Annals of Oncology*, **21**(3) 615-26.
- Chondrocoukis, G. & Papageorgiou, A. (2010) Diagnosing organizational culture of Greek public hospitals using the competing values framework. *Review of Clinical Pharmacology and Pharmacokinetics*, **28**, 269-78.
- CIS. (2009) *Atención a pacientes con enfermedades en fase terminal*. Madrid: CIS.
- Clark, D. (2007) From margins to centre: a review of the history of palliative care in cancer. *The Lancet Oncology*, **8**(5) 430-8.

-
- Clark, D. & Seymour, J. (1999) *Reflections on Palliative Care*. , Buckingham: Open University Press.
- Clark, D. (2010) The dilemma of goodness: acknowledging beneficence tension in the search for consensus. *Journal of the American Board of Family Medicine*, **23**(5), 674-6.
- Clark, J. (2003) Patient centred death. *British Medical Journal*, **327**(7408) 174-5.
- Cohen, S. R. & Leis, A. (2002) What determines the quality of life of terminally ill cancer patients from their own perspective? *Journal of Palliative Care*, **18**(1) 48-58.
- Cohen, J., Marcoux, I., Bilsen, J., Deboosere, P., van der Wal, G. & Deliens, L. (2006) European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Social Science & Medicine*, **63**(3) 743-756.
- Cohen, J., Houttekier, D., Onwuteaka-Philipsen, B., Miccinesi, G., Addington-Hall, J., Kaasa, S., Bilsen, J. & Deliens, L. (2010) Which patients with cancer die at home? A study of six European countries using death certificate data. *Journal of Clinical Oncology*, **28**(13), 2267-73.
- Copp, G. (1998) A review of current theories of death and dying. *Journal of Advanced Nursing*, **28**(2) 382-90.
- Corli, O., Apolone, G., Pizzuto, M., Cesaris, L., Cozzolino, A., Orsi, L. & Enterri, L. (2009) Illness awareness in terminal cancer patients: an Italian study. *Palliative Medicine*, **23**(4) 354-9.
- Corr, C.A. (1992) A task-based approach to coping with dying. *Omega*, **24**(2), 81-94.
- Corr, C.A., Doka, K.J. & Kastenbaum, R. (1999) Dying and its interpreters: A review of selected literature and some comments on the state of the field. *Omega: The Journal of Death and Dying*, **39**(4), 239-260.
- Costantini, M., Beccaro, M. & Merlo, F. (2005) The last three months of life of Italian cancer patients. Methods, sample characteristics and response rate of the Italian Survey of the Dying of Cancer (ISDOC). *Palliative Medicine*, **19**(8), 628-38.
- Costaon-Schou, K. & Hewison, J. (1999) *Experiencing Cancer: Quality of Life in Treatment*, Buckingham: Open University Press.
- Creswell, J. (2003) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 2nd. Thousand Oaks: Sage Publications.
- Critical Appraisal Skills Programme (CASP) (2010) Qualitative Research checklist. (Online) Available: <http://www.casp-uk.net/> (Assessed November 2011).
- Cummings, J.M. (2002) Exploring family systems nursing and the community children's nurse's role in caring for children with cystic fibrosis. *Journal of Child Health Care*, **6**(2), 120-32.
- Curtis, J.R. (2008) Palliative and end-of-life care for patients with severe COPD. *The European Respiratory Journal*, **32**(3), 796-803.
- Cutcliffe, J.R. (2005) Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, **51**(4), 421-8.

-
- Cutcliffe, J.R. & McKenna, H.P. (1999) Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing*, **30**(2), 374-80.
- Dalla-Vorgia, P., Katsouyanni, K., Garanis, T. N., Touloumi, G., Drogari, P. & Koutselinis, A. (1992) Attitudes of a Mediterranean population to the truth-telling issue. *Journal of Medical Ethics*, **18**(2) 67-74.
- Danforth, L. M. (1982) *The Death rituals of rural Greece.*, Princeton: Princeton University Press.
- Davies, C. (1999) *Reflexive Ethnography* London: Routledge.
- Dennis, G. T. (2001) Death in Byzantium, in Talbot, A. M. (ed.) *Dumbarton Oaks Papers*, No 55., Washington: Dunbardon Oaks Research Library and Collection
- Denzin, N. K. (1998) *Interpretive Ethnography: Ethnographic Practices for the 21st Century.*, Thousand Oaks: Sage Publications.
- Denzin, N.K. & Lincoln, Y.S. (2005) *The Sage Handbook of Qualitative Research*, London: Sage Publications.
- Department of Greek and Roman Art (2000) Death, Burial, and the Afterlife in Ancient Greece. In *Heilbrunn Timeline of Art History*. New York, The Metropolitan Museum of Art. [Online]. Available: http://www.metmuseum.org/toah/hd/dbag/hd_dbag.htm [Accessed February 2013]
- Department of Health. (2008) *End of Life Care Strategy - Promoting High Quality Care for All Adults at the End of Life*. London: Department of Health.
- de Pentheny O'Kelly, C., Urch, C. & Brown, E.A. (2011) The impact of culture and religion on truth telling at the end of life. *Nephrology Dialysis Transplantation*, **26**(12), 3838-42.
- Dionne-Odom, J.N. & Bakitas, M. (2012) Why Surrogates Don't Make Decisions the Way We Think They Ought to: Insights From Moral Psychology. *Journal of Hospice & Palliative Nursing*, **14**(2), 99-106.
- Dobratz, M.C. (2002) The pattern of the becoming-self in death and dying. *Nursing Science Quarterly*, **15**(2), 137-42
- Donnelly, S. & Walsh, D. (1996) Quality of life assessment in advanced cancer. *Palliative Medicine*, **10**(4) 275-83.
- Dossios, T., Markopoulos, C., Vlachos, I. & Liatsos, P. (1986) *Aspects of Greek doctors on the subject if the cancer patient should know his disease. Hellenic Armed Forces Medicine Review* **20**, 309-315.
- Doyle, D. (1999) *The Platform Ticket: Memories and Musings of a Hospice Doctor*, Durham: The Pentland Press
- Dracopoulou, S. & Doxiadis, S. (1988) In Greece, Lament for the Dead, Denial for the Dying. *Hastings Center Report*, **18**(4) 15-16.
- EAPC. (2010a) *The Budapest Commitments a framework for palliative care development* [Online]. Available: <http://www.eapcnet.eu/Themes/Policy/Budapestcommitments/BClistbycountry.aspx> [Accessed October 2012].

-
- EAPC. (2010b) *EAPC Task Force Country Report – Greece* [Online]. Available: <http://www.eapc-taskforce-development.eu/countries/country.php?cid=9> [Accessed October 2012].
- Economist Intelligence Unit. (2010) *The Quality of Death: Ranking end-of-life care across the world*. London: Economist Intelligence Unit
- Edmonds, P., Vivat, B., Burman, R., Silber, E. & Higginson, I.J. (2007) Fighting for everything': service experiences of people severely affected by multiple sclerosis. *Multiple Sclerosis*, **13**(5), 660-7.
- Ellershaw, J. & Ward, C. (2003) Care of the dying patient: the last hours or days of life. *British Medical Journal*, **326**(7379), 30-4.
- Ellingson, L. (2009) *Engaging Crystallization in Qualitative Research: An Introduction*, Sage, California.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D. & Emanuel, L.L. (1999) Assistance from Family Members, Friends, Paid Care Givers, and Volunteers in the Care of Terminally Ill Patients. *New England Journal of Medicine*, **341**(13), 956-63.
- Emerson, R. M., Fretz, E. I. & Shaw, L. L. (2001) Participant observation and fieldnotes, in Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds.) *Handbook of Ethnography*, London: Sage.
- Epstein, A.M., Hall, J.A., Tognetti, J., Son, L.H. & Conant, L., Jr. (1989) Using proxies to evaluate quality of life. Can they provide valid information about patients' health status and satisfaction with medical care? *Medical Care*, **27**(3 Suppl), S91-8.
- Erickson, J. (2013) Bedside nurse involvement in end-of-life decision making: a brief review of the literature. *Dimensions of critical care nursing*, **32**(2), 65-8.
- ET-1 (2012) *ΙΧΝΗΛΑΤΩΝΤΑΣ: "Γαλιλαία: Κύτταρο ζωής και ελπίδας"*. [Online] Available: http://www.ert.gr/webtv/et1/item/9754-Mia-sygchronh-Galilaia-28-12-2012#.UVN1oTea_To [accessed February 2013]
- Evans, N. & Walsh, H. (2002) The organisation of death and dying in today's society. *Nursing Standard*, **16**(25) 33-8.
- Fainsinger, R. L., Nunez-Olarte, J. M. & Demoissac, D. M. (2003) The cultural differences in perceived value of disclosure and cognition: Spain and Canada. *Journal of Palliative Care*, **19**(1) 43-8.
- Fernandez Suarez, A., Fernandez Alvarez, T., Alonso Arruquero, C., Marcilla Escotet, M., Cortina Viesca, A., Conde Rodriguez, M. & Rubio Dominguez, J. (2002) [Attitudes of health centre users to diagnoses of terminal illness]. *Aten Primaria*, **30**(7) 449-54.
- Ferrell, B.R., Ferrell, B.A., Rhiner, M. & Grant, M. (1991) Family factors influencing cancer pain management. *Postgraduate Medical Journal*, **67 Suppl 2**, S64-9.
- Field, D. (1994) Palliative medicine and the medicalization of death. *European journal of cancer care*, **3**(2) 58-62.
- Field, D. (1996) Awareness and modern dying. *Mortality*, **1**(3), 255-65.
- Field, D. & Copp, G. (1999) Communication and awareness about dying in the 1990s. *Palliative Medicine*, **13**(6) 459-68.

-
- Finlay, I. G., Higginson, I. J., Goodwin, D. M., Cook, A. M., Edwards, A. G. K., Hood, K., Douglas, H.-R. & Normand, C. E. (2002) Palliative care in hospital, hospice, at home: results from a systematic review. *Annals of Oncology*, **13**(suppl 4) 257-264.
- Flick, U. (2009) *An Introduction to Qualitative Research*, Thousand oaks: Sage.
- Fraser, C. (1999) The experience of transition for a daughter caregiver of a stroke survivor. *The Journal of Neuroscience Nursing*, **31**(1), 9-16.
- Furst, C. J., de Lima, L., Praill, D. & Radbruch, L. (2009) An update on the Budapest Commitments. *European Journal of Palliative Care*, **16**(1) 22-5.
- Galilee. (2012) *Galilee Palliative Care Unit Website* [Online]. Available: <http://www.galilee.gr/general-information> [Accessed November 2012].
- Garland, R. (1985) *The Greek Way of Death*. Ithaca, N.Y. Cornell University Press,
- Georgaki, S., Kalaidopoulou, O., Liarmakopoulos, I. & Mystakidou, K. (2002) Nurses' attitudes toward truthful communication with patients with cancer. A Greek study. *Cancer Nursing*, **25**(6) 436-41.
- George, L.K. (2002) Research design in end-of-life research state of science. *The Gerontologist*, **42**(suppl 3), 86-98.
- Giannini, A., Pessina, A. & Tacchi, E. M. (2003) End-of-life decisions in intensive care units: attitudes of physicians in an Italian urban setting. *Intensive Care Medicine*, **29**(11) 1902-10.
- Giddens, A. (1984) *The Constitution of Society: Outline of the Theory of Structuration*: University of California Press.
- Gika, M. (1998) *Euthanasia: The dilemma in everyday nursing practice*. . PhD, University of Athens.
- Given, B.A., Given, C.W. & Kozachik, S. (2001) Family Support in Advanced Cancer. *CA: A Cancer Journal for Clinicians*, **51**(4), 213-31.
- Glaser, B. G. & Strauss, A. L. (1965) Temporal Aspects of Dying as a Non-Scheduled Status Passage. *American Journal of Sociology*, **71**(1) 48-59.
- Glaser, B.G. & Strauss, A.L. (1968) *Time for Dying*, Chicago: Aldine
- Goelz, T., Wuensch, A., Stubenrauch, S., Ihorst, G., de Figueiredo, M., Bertz, H., Wirsching, M. & Fritzsche, K. (2011) Specific training program improves oncologists' palliative care communication skills in a randomized controlled trial. *Journal of Clinical Oncology*, **29**(25), 3402-7.
- Goldberg, R.J. & Wool, M.S. (2010) Psychotherapy for the spouses of lung cancer patients: assessment of an intervention. *Psychotherapy and Psychosomatics*, **43**(3), 141-50.
- Goldstein, D., Thewes, B. & Butow, P. (2002) Communicating in a multicultural society II: Greek community attitudes towards cancer in Australia. *Internal Medicine Journal*, **32**(7) 289-96.
- Gomes, B., Calanzani, N. & Higginson, I. J. (2012) Reversal of the British trends in place of death: Time series analysis 2004–2010. *Palliative Medicine*, **26**(2) 102-7.
- Goodell, T.T. & Hanson, S.M.H. (1999) Nurse-family interactions in adult critical care: a Bowen family systems perspective. *Journal of Family Nursing*, **5**(1), 72-91.

-
- Grande, G. & Ewing, G. (2008) Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliative Medicine*, **22**(8), 971-2.
- Grassi, L., Giraldi, T., Messina, E. G., Magnani, K., Valle, E. & Cartei, G. (2000) Physicians' attitudes to and problems with truth-telling to cancer patients. *Supportive Care in Cancer*, **8**(1) 40-5.
- Graves, R. (1970) *Greek Myths*, London: Penguin.
- Guba, E.G. & Lincoln, Y.S. (1994) Competing paradigms in qualitative research In Denzin, N. K. and Lincoln, Y. S. (eds.) *Handbook of Qualitative Research*, London: SAGE.
- Griffiths, P. (2008) Ethical conduct and the nurse ethnographer: consideration of an ethic of care. *Journal of Research in Nursing*, **13**(4), 350-61.
- Grove, S.K., Burns, N. & Gray, J. (2012) *The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence*, St. Louis, MO.: Saunders.
- Gubrium, J. F. & Holstein, J. (2003) Analysing interpretive practice in Denzin, N. K. & Lincoln, Y. (eds.) *Strategies of Qualitative Inquiry*, Thousand Oaks: Sage Publications.
- Gysels, M., Evans, N., Meñaca, A., Andrew, E., Toscani, F., Finetti, S., Pasman, H. R., Higginson, I., Harding, R. & Pool, R. (2012) Culture and End of Life Care: A Scoping Exercise in Seven European Countries. *PLoS ONE*, **7**(4) e34188.
- Hales, S., Zimmermann, C. & Rodin, G. (2008) The quality of dying and death. *Archives of Internal Medicine*, **168**(9), 912-8.
- Hamilton, D. (1994) Traditions, preferences and postures in applied qualitative research in Denzin, N. K. & Lincoln, Y. (eds.) *Handbook of Qualitative Research*, 1st. Thousand Oaks: Sage Publications.
- Hammersley, M. (1998) *Reading Ethnographic Research: A Critical Guide*, London: Longman.
- Hammersley, M. (2002) Ethnography and the disputes over validity in Walford, G. (ed.) *Debates and Developments in Ethnographic Methodology* Oxford: Elsevier Science.
- Hammersley, M. & Atkinson, P. (1983) *Ethnography: Principles in Practice*, London: Tavistock.
- Hammersley, M. & Atkinson, P. (1995) *Ethnography: Principals in practice*, 2nd. London: Routledge.
- Hancock, K., Clayton, J.M., Parker, S.M., Walder, S., Butow, P.N., Carrick, S., Currow, D., Gheri, D., Glare, P., Hagerty, R. & Tattersall, M.H. (2007) Discrepant perceptions about end-of-life communication: a systematic review. *Journal of Pain and Symptom Management*, **34**(2), 190-200.
- Hatzinicholaou, N. (2003) *Values of orthodox bioethical speculations. Congress of Bioethics committee of Greek Orthodox Christian Church*. [Online]. Available: http://www.bioethics.org.gr/013_Sinedriofr.html [Accessed January 2013].
- Hearn, J. & Higginson, I. (1999) Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Quality in Health Care*, **8**(219 - 227).

-
- Heron, J. (1977) *Catharsis in Human Development*, London: University of London: British Postgraduate Medical Federation & Human Research Project
- Heyl, B. S. (2001) Ethnographic interviewing, in Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds.) *Handbook of Ethnography*, London: Sage.
- Hinton, J. (1994) Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Medicine*, **8**(3) 183-96.
- Hilton, E.L. (2002) The meaning of stroke in elderly women: a phenomenological investigation. *Journal of Gerontological Nursing*, **28**(7), 19-26.
- Hockey, J. (1990) *Experiences of Death: An Anthropological Account*, Edinburgh: Edinburgh University Press.
- Holloway, I. & Wheeler, S. (1996) *Qualitative Research for Nurses*, Oxford: Blackwell Science.
- Hudson, P.L., Aranda, S. & Kristjanson, L.J. (2004) Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *Journal of Palliative Medicine*, **7**(1), 19-25.
- Hughes, R., Aspinall, F., Addington-Hall, J., Chidgey, J., Drescher, U., Dunkley, M. & Higginson, I. J. (2003) Professionals' views and experiences of using outcome measures in palliative care. *International Journal of Palliative Nursing*, **9**(6) 234-8.
- IAHPC. (2004) Working to improve access to palliative care. *Palliative Medicine*, **18**, 491-493.
- Iconomou, G., Vagenakis, A. G. & Kalofonos, H. P. (2001) The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. *Supportive Care in Cancer*, **9**(8) 591-6.
- Ikonomidis, B. D. (1966) *The Grief of the Deceased in Greece*. : Greek Folklore Centre.
- Inglehart, R & Welzel, C. (2010) Changing Mass Priorities: The Link between Modernization and Democracy. *Perspectives on Politics*, **8** (2) 554
- Ingleton, C. (1997) Evaluating Palliative Care Services: An Analysis of Two Hospices in One Health District. Unpublished PhD thesis, University of Sheffield.
- Ioannidou E, G. E. (2008) The recent code of medical deontology, the cancer patient informing process and the involvement of the greek family. *Archives of Hellenic Medicine*, **25**(2) 224-30.
- Janesick, V.J. (2000) The choreography of qualitative research design: Minuets, improvisations, and crystallization. In N. Denzin & Y. Lincoln (eds.) *The Sage Handbook of Qualitative Research*, London: SAGE
- Johnston, G. & Abraham, C. (2000) Managing awareness: negotiating and coping with a terminal prognosis. *International Journal of Palliative Nursing*, **6**(10), 485-94.
- Kaasa, S. & Loge, J. H. (2003) Quality of life in palliative care: principles and practice. *Palliative Medicine*, **17**(1) 11-20.
- Kanitsaki, O. (1988) Transcultural nursing: challenge to change. *The Australian Journal of Advanced Nursing*, **5**(3) 4-11.
- Karanis, M. (1994) *Biomedical Evolution and Constitutional Law*. , Athens: Sakkoulas.

-
- Karp, I. & Kendall, M. B. (2001) Reflexivity in fieldwork in Bryman, A. (ed.) *Analysis and Writing in Ethnography*, London: Sage Publications.
- Kastanioti, C., Siouroumni, E., Mavridoglou, G. & Polizos, N. (2011) ΕΡΓΑΣΙΑ, ΕΠΕΥΝΗΤΙΚΗ. "Συγκριτική αξιολόγηση οργανωσιακής κουλτούρας μονάδων υγείας." *Archives of Hellenic Medicine*, **28**(1), 70-8.
- Katsimigas, G., Maragouti, E., Spiliopoulou, C. H. & Gika, M. (2007) Nursing the theological access to death. *Nosileftiki*, **46**(4) 441-52.
- Kazdaglis, G.A., Arnaoutoglou, C., Karypidis, D., Memekidou, G., Spanos, G. & Papadopoulos, O. (2010) Disclosing the truth to terminal cancer patients: a discussion of ethical and cultural issues. *Eastern Mediterranean Health Journal*, **16**(4), 442-7.
- Kelley, P. & Callanan, M. (1992) *Final Gifts*, New York: Poseidon Press.
- Kelly, D. (2002) *In the company of men: Embodiment and prostate cancer* Goldsmith's College.
- Kennedy, C. (1999) Participant observation as a research tool in a practice based profession *Nurse Researcher*, **7**(1) 56-65.
- King, D.A. & Quill, T. (2006) Working with families in palliative care: One size does not fit all. *Journal of Palliative Medicine*, **9**(3), 704-15.
- Kirk, J. & Miller, M. (1986) *Reliability and validity in qualitative research.*, Beverly Hills, CA: Sage.
- Kirk, P., Kirk, I. & Kristjanson, L.J. (2004) What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *British Medical Journal*, **328**(7452), 1343.
- Koop, P.M. & Strang, V.R. (2003) The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research*, **12**(2), 127-44.
- Koufos, I. N. (1970) *Ta ellinika dimotika tragoudia*, Athens.
- Koutselinis, A. (2000) Euthanasia. *Iatriki Epikerotita*, 781-86.
- Kralik, D., Koch, T. & Eastwood, S. (2003) The salience of the body: transition in sexual self-identity for women living with multiple sclerosis. *Journal of Advanced Nursing*, **42**(1), 11-20.
- Kralik, D., Visentin, K. & Van Loon, A. (2006) Transition: a literature review. *Journal of Advanced Nursing*, **55**(3), 320-9.
- Kubler-Ross, E. (1969) *On Death and Dying* New York: The Macmillan Co
- Kubler Ross, E. (1975) *Death: the final stage of growth*, Englewood Cliffs, NJ.: Prentice Hall.
- Lamentations before the Holy Sepulchre (2003) New Byzantium Publications Williamston, Michigan
- Lavrentiadis, G., Manos, N., Christakis, J. & Semoglou, C. (1988) The Greek cancer patient's knowledge and attitudes towards his diagnosis and prognosis. *Psychotherapy and psychosomatics*, **49**(3-4) 171-8.
- Lawton, J. (2000) *The Dying Process. Patients' Experiences of Palliative Care.*, London: Routledge.

-
- LeCompte, M. D. & Goetz J, P. (2001) Problems of reliability and validity in ethnographic research, in Bryman, A. (ed.) *Ethnography*, London: Sage Publications.
- Leming, M.R. & Dickinson, G.E. (2010) *Understanding Dying, Death, and Bereavement*, Belmont, CA: Wadsworth Publishing Company.
- Lentza, V., Montgomery, A.J., Georganta, K. & Panagopoulou, E. (2013) Constructing the health care system in Greece: responsibility and powerlessness. *British journal of health psychology*, **31**(10), 12028.
- Liadinis, D. (1992) *The Greeks*, Athens: Vivliogonia Editions.
- Liakopoulos, I., Kakabouras, M., Kolovos, I. & Hristopoulou, I. (2010) The dilemma of euthanasia: exploring the attitudes of nurses. *To βήμα του Ασκληπιού*, **9**(2) 205-11.
- Lin, M.L., Pang, M.C. & Chen, C.H. (2012) Family as a whole: elective surgery patients' perception of the meaning of family involvement in decision making. *Journal of Clinical Nursing*, **22**(1-2), 271-8.
- Lincoln, Y.S. (1995) Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, **1**(3), 275-89.
- Liturgy, T. D. (1995) *The Greek Orthodox Archdiocese of Thyateira and Great Britain*, Oxford: Oxford University Press.
- Locatelli, C. & Piselli, P. (2010) Telling bad news to the elderly cancer patients: the role of family caregivers in the choice of non-disclosure. *Journal of Geriatric Oncology*, **1**, 73-80.
- Lucchiari, C., Masiero, M., Pravettoni, G., Vago, G. & Wears, R. L. (2010) End-of-life decision-making: A descriptive study on the decisional attitudes of Italian physicians. *Life Span and Disability* **13**, 71–86.
- Lunney, J.R., Lynn, J., Foley, D.J., Lipson, S. & Guralnik, J.M. (2003) Patterns of functional decline at the end of life. *The Journal of The American Medical Association*, **289**(18), 2387-92.
- Lynch, T., Clark, D., Centeno, C., Rocafort, J., de Lima, L., Filbet, M., Hegedus, K., Belle, O., Giordano, A., Guillén, F. & Wright, M. (2010) Barriers to the development of palliative care in Western Europe. *Palliative Medicine*, **24**(8) 812-819.
- Lynch, T., Clark, D. & Connor, S. R. (2011) *Mapping levels of palliative care development: A global update 2011*. Worldwide Palliative Care Alliance.
- Lynn, J. (1997) Measuring quality of care at the end of life: a statement of principles. *Journal of the American Geriatrics Society*, **45**(4) 526-7.
- Lynn, J. & Adamson, D. M. (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. Santa Monica, CA: Rand.
- MacKenzie, C. & Stoljar, N. (2000) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, Oxford: Oxford University Press.
- Mancuso, L. (2009) Providing culturally sensitive palliative care. *Nursing*, **39**(5) 50-3.
- Manne, S. & Badr, H. (2008) Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer*, **112**(S11), 2541-55.

-
- Manos, N. & Christakis, J. (1980) Attitudes of cancer specialists toward their patients in Greece. *International Journal of Psychiatry in Medicine*, **10**,305.
- Mason, T. & Carton, G. (2002) Towards a 'forensic lens' model of multidisciplinary training. *Journal of Psychiatric and Mental Health Nursing*, **9**(5), 541-51.
- Martin-McDonald, K. & Biernoff, D. (2002) Initiation into a dialysis-dependent life: an examination of rites of passage. *Nephrology Nursing Journal*, **29**(4), 347-52.
- Martin-Moreno, J., Harris, M., Clark, D., Normand, C., Centeno, C. (2008) *Palliative Care in the European Union*. European Parliament, Policy Department: Economic and Scientific Policy.
- Marzano, M. (2007) "Secrets and lies": (not) telling bad news in Italian oncology. *Bulletin of the Transilvania University of Braşov*. 2 (51) 22-31.
- Mays, N. & Pope, C. (2000) Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, **320**(7226), 50-2.
- McKechnie, R., MacLeod, R. & Keeling, S. (2007) Facing uncertainty: the lived experience of palliative care. *Palliative & Supportive Care*, **5**(3), 255-64.
- McLeod, D.L., Tapp, D.M., Moules, N.J. & Campbell, M.E. (2010) Knowing the family: Interpretations of family nursing in oncology and palliative care. *European Journal of Oncology Nursing*, **14**(2), 93-100.
- McMillan, S.C., Small, B.J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L. & Haley, W.E. (2006) Impact of coping skills intervention with family caregivers of hospice patients with cancer. *Cancer*, **106**(1), 214-22.
- McNamara, B. (2001) *Fragile Lives: Death, Dying and Care*, Buckingham: Open University Press
- Mehta, A., Cohen, S.R. & Chan, L.S. (2009) Palliative care: a need for a family systems approach. *Palliative and Supportive Care*, **7**(2), 235-43.
- Meleis, A.I., Sawyer, L.M., Im, E.-O., Hilfinger Messias, D.K. & Schumacher, K. (2000) Experiencing Transitions: An Emerging Middle-Range Theory. *Advances in Nursing Science*, **23**(1), 12-28.
- Millar, C., Reid, J. & Porter, S. (2013) Refractory cachexia and truth-telling about terminal prognosis: a qualitative study. *European Journal of Cancer Care*, **22**(3), 326-33.
- Ministry of Health. (2005) *Draft code of medical practise and deontology (Translated from Greek - Υπουργείο Υγείας. Προτεινόμενο σχέδιο κώδικα άσκησης ιατρικού επαγγέλματος και δεοντολογίας)*.
- Mischler, E. (1986) *Research Interviewing: Context and Narrative* Cambridge, MA: Harvard University Press.
- Moore, L. & Savage, J. (2002) Participant observation, informed consent and ethical approval. *Nurse Researcher*, **9**(4) 58-69.
- Morse, J.M. & Field, P.A. (1996) *Nursing Research: The Application of Qualitative Approaches*, Nelson Thornes.
- Muecke, M.A. (1994) On the evaluation of ethnographies. *Critical issues in qualitative research methods*, Thousand Oaks, CA: Sage. Publications, pp. 187-209

-
- Mulhall, A. (2003) In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*, **41**(3) 306-13.
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S. & Watson, P. (1998) Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*, **2**(16), 1-209.
- Murphy, E. & Dingwall, R. (2001) The ethics of ethnography, in Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds.) *Handbook of Ethnography*, London: Sage Publications.
- Murphy, F. (2005) Preparing for the field: developing competence as an ethnographic field worker. *Nurse Researcher*, **12**(3), 52-60.
- Murray, S. A. (2000) Out of Africa: some lessons for general practice/family medicine in developed countries? *Family Practice*, **17**(5) 361-3.
- Murray, S.A., Kendall, M., Boyd, K. & Sheikh, A. (2005) Illness trajectories and palliative care. *British Medical Journal*, **330**(7498), 1007-11.
- Murray, S.A. & Sheikh, A. (2006) Serial interviews for patients with progressive diseases. *The Lancet*, **368**(9539), 901-2.
- Murray, S.A., Kendall, M., Grant, E., Boyd, K., Barclay, S. & Sheikh, A. (2007) Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *Journal of Pain and Symptom Management*, **34**(4), 393-402.
- Murtagh, F., Preston, M. & Higginson, I. (2004) Patterns of dying: palliative care for non-malignant disease. *Clinical Medicine*, **4**(1), 39-44.
- Murtagh, F.E., Murphy, E. & Sheerin, N.S. (2008) Illness trajectories: an important concept in the management of kidney failure. *Nephrology Dialysis Transplantation*, **23**(12), 3746-8.
- Murtagh, F. E. M., Sheerin, N. S., Addington-Hall, J. & Higginson, I. J. (2011) Trajectories of Illness in Stage 5 Chronic Kidney Disease: A Longitudinal Study of Patient Symptoms and Concerns in the Last Year of Life. *Clinical Journal of the American Society of Nephrology*, **6**(7) 1580-90.
- Mystakidou, K., Liossi, C., Vlachos, L. & Papadimitriou, J. (1996) Disclosure of diagnostic information to cancer patients in Greece. *Palliative Medicine*, **10**(3) 195-200.
- Mystakidou, K., Liossi, C., Fragiadakis, K., Georgaki, S. & Papadimitriou, J. (1998) What do Greek physicians know about managing cancer pain? *Journal of Cancer Education*, **13**(1) 39-42.
- Mystakidou, K., Tsilika, E., Befon, S., Kululias, V. & Vlahos, L. (1999) Quality of life as a parameter determining therapeutic choices in cancer care in a Greek sample. *Palliative Medicine*, **13**(5) 385-92.
- Mystakidou, K., Parpa, E., Tsilika, E., Georgaki, S., Mavromati, A. & Vlahos, L. (2002a) Quality of life in terminally ill cancer patients. *European Journal of Palliative Care*, **9**(6) 252-5.
- Mystakidou, K., Parpa, E., Tsilika, E., Kalaidopoulou, O. & Vlahos, L. (2002b) The families evaluation on management, care and disclosure for terminal stage cancer patients. *BMC Palliative Care*, **1**(1) 3.

-
- Mystakidou, K., Tsilika, E., Parpa, E., Katsouda, E. & Vlahos, L. (2003) A Greek perspective on concepts of death and expression of grief, with implications for practice. [Review] [38 refs]. *International Journal of Palliative Nursing*, **9**(12) 534-7.
- Mystakidou, K., Parpa, E., Tsilika, E., Katsouda, E. & Vlahos, L. (2004) Cancer information disclosure in different cultural contexts. *Supportive Care in Cancer*, **12**(3) 147-54.
- Mystakidou, K., Tsilika, E., Parpa, E., Katsouda, E. & Vlahos, L. (2005) Patterns and barriers in information disclosure between health care professionals and relatives with cancer patients in Greek society. *European Journal of Cancer Care*, **14**(2) 175-81.
- Mystakidou, K., Parpa, E., Tsilika, E., Pathiaki, M., Hatzipli, I., Galanos, A. & Vlahos, L. (2008) The experience of hopelessness in a population of Greek cancer patients receiving palliative care. *International Journal of Social Psychiatry*, **54**(3) 262-71.
- Mystakidou, K., Parpa, E., Tsilika, E., Galanos, A., Patiraki, E., Tsiatas, M. & Vlahos, L. (2009a) Where Do Cancer Patients Die in Greece? A Population-Based Study on the Place of Death in 1993 and 2003. *Journal of Pain and Symptom Management*, **38**(2) 309-14.
- Mystakidou, K., Parpa, E., Tsilika, E., Panagiotou, I., Galanos, A., Tsiatas, M. & Theodorakis, P. (2009b) The Incidence of Place of Death in Greek Patients with Cancer in 1995 and 2005. *The American Journal of Hospice & Palliative Care*, **26**(5) 347-53
- Mystakidou, K., Tsilika, E., Parpa, E., Gogou, P., Theodorakis, P. & Vlahos, L. (2010) Self-efficacy beliefs and levels of anxiety in advanced cancer patients. *European Journal of Cancer Care*, **19**(2) 205-11.
- Mystakidou, K., Tsilika, E., Parpa, E., Panagiotou, I., Galanos, A. & Gouliamos, A. (2011) The mediation effect of anxiety between post-traumatic stress symptoms and preparatory grief in advanced cancer patients. *Journal of Pain & Symptom Management*, **41**(3) 511-21.
- National Cancer Institute (NCI) (2012) Family caregivers in cancer: roles and challenges (PDQ). (Online) Available: <http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/healthprofessional> (Assessed March 2013)
- National Institute for Health and Clinical Excellence (NICE) (2007) Methods for the development of NICE public health Quality appraisal checklist for qualitative studies London: National Institute for Health and Clinical Excellence.
- National Institute for Health and Care Excellence (NICE) (2012) Methods for the development of NICE public health guidance: Quality appraisal checklist – qualitative studies, (Online) Available: <http://publications.nice.org.uk/methods-for-the-development-of-nice-public-health-guidance-third-edition-pmg4/appendix-h-quality-appraisal-checklist-qualitative-studies> (Assessed February 2013)
- Namei, S.K., King, M.O., Byrne, M. & Proffitt, C. (1993) The ethics of role conflict in research. *The Journal of Neuroscience Nursing*, **25**(5), 326-30.
- Nissim, R., Rennie, D., Fleming, S., Hales, S., Gagliese, L. & Rodin, G. (2012) Goals Set in the Land of the Living/Dying: A Longitudinal Study of Patients Living with Advanced Cancer. *Death Studies*, **36**(4), 360-90.

-
- Noussias, M., Athitakes, K., Garas, I., Daskalopoulos, G., Lyketsos, X., Betsides, N., Bratsiotis, N. & Sakkas, N. (1975) *Roundtable discussion: should cancer patients be informed?* . *Bulletin of Science Union Athens Municipal Hospital* 6, 7–51.
- Nunez Olarte, J. M. & Guillen, D. G. (2001) Cultural issues and ethical dilemmas in palliative and end-of-life care in Spain. *Cancer Control*, **8**(1) 46-54.
- Nursing and Midwifery Council (NMC) (2010a) Statutory competencies-Adult Nursing. (Online) Available: <http://bit.ly/Y0dybh> (Accessed 8 March 2013).
- Nursing and Midwifery Council (NMC)(2010b) Standards for education. Standard 7. Requirement R7 1.3. . (Online) Available: <http://bit.ly/Z5Ax6g> (Accessed 8 March 2013).
- Nursing, UOA: *Post graduate studies, Nursing school, university of Athens*. [Online] Available: <http://www.nurs.uoa.gr/metaptyxiakes-spydes/pms/symbatiko-pms.html> [Accessed December 2012]
- Obessi, P. (2011) Limits of provision of patients information by doctors and nurses: the legal approach. *Nosileftiki*, **50**(1) 30-4.
- Oldham, L. & Kristjanson, L.J. (2004) Development of a pain management programme for family carers of advanced cancer patients. *International Journal of Palliative Nursing*, **10**(2), 91-9.
- Oliver, D. P., Porock, D. & Zweig, S. (2004) End-of-Life Care in U.S. Nursing Homes: A Review of the Evidence. *Journal of the American Medical Directors Association*, **5**(3) 147-55.
- Osuna, E., Perez-Carceles, M. D., Esteban, M. A. & Luna, A. (1998) The right to information for the terminally ill patient. *Journal of Medical Ethics*, **24**(2) 106-9.
- Panourgia, N. (1995) *Fragments of Death, Fables of Identity: an Athenian Anthropography.* , Madison: University of Wisconsin Press
- Papadatou, D. (2001) Paediatric care. The evolution of palliative care for children in Greece. *European Journal of Palliative Care*, **8**(1) 35-8.
- Papadimitriou, M., Argyrou, E. & Paleogianni, V. (1998) Emotional support of cancer patients: the nursing approach. *Cancer Nursing*, **21**(4) 246-51.
- Pardon, K., Deschepper, R., Vander Stichele, R., Bernheim, J.L., Mortier, F., Schallier, D., Germonpre, P., Galdermans, D., Kerckhoven, W.V. & Deliens, L. (2012a) Preferred and actual involvement of advanced lung cancer patients and their families in end-of-life decision making: a multicenter study in 13 hospitals in Flanders, Belgium. *Journal of Pain and Symptom Management*, **43**(3), 515-26.
- Pardon, K., Deschepper, R., Vander Stichele, R., Bernheim, J.L., Mortier, F., Bossuyt, N., Schallier, D., Germonpre, P., Galdermans, D., Kerckhoven, W. & Deliens, L. (2012b) Changing preferences for information and participation in the last phase of life: a longitudinal study among newly diagnosed advanced lung cancer patients. *Supportive Care in Cancer*, **20**(10), 2473-82.
- Parpa, E., Mystakidou, K., Tsilika, E., Sakkas, P., Patiraki, E., Pistevou-Gombaki, K., Galanos, A. & Vlahos, L. (2006) The attitudes of Greek physicians and lay people on

- euthanasia and physician-assisted suicide in terminally ill cancer patients. *American Journal of Hospice & Palliative Medicine*, **23**(4) 297-303.
- Parpa, E., Mystakidou, K., Tsilika, E., Sakkas, P., Patiraki, E., Pisteovou-Gombaki, K., Govina, O., Panagiotou, I., Galanos, A. & Gouliamos, A. (2010) Attitudes of health care professionals, relatives of advanced cancer patients and public towards euthanasia and physician assisted suicide. *Health Policy*, **97**(2-3) 160-5.
- Parkes, C.M. (1988) Bereavement as a psychosocial transition: Processes of adaptation to change. *Journal of Social Issues*, **44**(3), 53-65.
- Pattison, E.M. (1977) *The Experience of Dying*, Englewood Cliffs, NJ: Prentice-Hall.
- Patton, M.Q. (2005) Qualitative research. In *Encyclopedia of Statistics in Behavioral Science*Wiley Online Library, DOI: 10.1002/0470013192.bsa514.
- Payne, S. (2010) EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. *European Journal of Palliative Care*, **17**(5), 238-45.
- Pellatt, G. (2003) Ethnography and reflexivity: emotions and feelings in fieldwork. *Nurse Researcher*, **10**(3) 28-37.
- Peruselli, C., Di Giulio, P., Toscani, F., Gallucci, M., Brunelli, C., Costantini, M., Tamburini, M., Paci, E., Miccinesi, G., Addington-Hall, J. M. & Higginson, I. J. (1999) Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliative Medicine*, **13**(3) 233-41.
- Pilkington, F. B. & Mitchell, G. J. (2004) Quality of life for women living with a gynecologic cancer. *Nursing science quarterly*, **17**(2) 147-55.
- Plant, H. (1996) Research interviewing. *Palliative Medicine*, **10**(4), 339-41.
- Polit, D. & Hungler, B. (1995) Essentials of nursing research: methods, appraisal, and utilization. *Journal of Nursing Staff Development* **10**(3), 175-8.
- Polit, D. F. & Beck, C. T. (2004) *Nursing Research*, 7th Philadelphia: Lippincott Williams & Wilkins.
- Pope, C. & Mays, N. (2008) *Qualitative Research in Health Care*, Oxford: BMJ.
- Porta, M., Busquet, X. & Jarrod, M. (1997) Attitudes and views of physicians and nurses towards cancer patients dying at home. *Palliative Medicine*, **11**(2) 116-26.
- Porter, S. (1995) *Nursing's Relationship with Medicine*. , Aldershot: Avebury.
- Powers, B.A. & Knapp, T.R. (1990) *A Dictionary of Nursing Theory and Research*, Newbury Park: Sage.
- Powis, J., Etchells, E., Martin, D. K., MacRae, S. K. & Singer, P. A. (2004) Can a "good death" be made better?: A preliminary evaluation of a patient-centred quality improvement strategy for severely ill in-patients. *BMC Palliat Care*, **3**(1) 2.
- Pronzato, P., Bertelli, G., Losardo, P. & Landucci, M. (1994) What do advanced cancer patients know of their disease? A report from Italy. *Supportive Care in Cancer*, **2**(4) 242-4.
- Psilaki, N. & Psilaki, M. (2001) *To psomi tw n ellinwn kai ta glikismata tis laikis mas paradosis*, Heraklion: Karmanor.

-
- Punch, M. (1994) Politics and Ethics in qualitative research, in Denzin, N. K. & Lincoln, Y. S. (eds.) *Handbook of Qualitative Research*, Thousand Oaks: Sage Publications.
- Quinn, K., Hudson, P., Ashby, M. & Thomas, K. (2008) "Palliative care: the essentials": evaluation of a multidisciplinary education program. *Journal of Palliative Medicine*, **11**(8), 1122-9.
- Radbruch, L., Payne, S. (2009) White Paper on standards and norms for hospice and palliative care in Europe: part 1. *European Journal of Palliative Care*, **16**(6) 278-89.
- Ramon, I., Alonso, J., Subirats, E., Yanez, A., Santed, R., Pujol, R. & Morir de Mayor en Cataluna Study, G. (2006) [Place of death of elderly persons in Catalonia]. *Revista Clínica Española*, **206**(11) 549-55.
- Raudonis, B. M. (1992) Ethical Considerations in Qualitative Research with Hospice Patients. *Qualitative Health Research*, **2**(2) 238-49.
- Redfield, J. M. (1992) *Tragedy of Hector- Nature and Civilisation in Iliad*, Athens: Evrialos Publications.
- Reimer, J.C., Davies, B. & Martens, N. (1991) Palliative care: The nurse's role in helping families through the transition of "fading away". *Cancer Nursing*, **14**(6), 321-7.
- Richardson, A. (2004) Creating a culture of compassion: developing supportive care for people with cancer. *European Journal of Oncology Nursing*, **8**(4) 293-305.
- Robertson, M. H. & Boyle, J. S. (1984) Ethnography: contributions to nursing research. *Journal of Advanced Nursing*, **9**(1) 43-9.
- Rodin, G. (2009) Individual psychotherapy for the patient with advanced disease. In Chochinov, H. M. and Breitbart, W. (eds.) *Handbook of Psychiatry in Palliative Medicine* Oxford University, New York, pp. 443-53.
- Rolfe, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, **53**(3), 304-10.
- Rossen, E.K. (1998) Older Women in Relocation Transition. PhD Thesis. Chicago: University of Illinois, Health Sciences Center.
- Rudge, T. (1996) (Re) writing ethnography: the unsettling questions for nursing research raised by post-structural approaches to 'the field'. *Nursing Inquiry*, **3**(3) 146-52.
- Sandman, L. (2005) *A Good Death: on the Value of Death and Dying*, New York: Open University Press.
- Sarantakos, S. (1993) *Social Research*, South Melbourne: Macmillan.
- Sarfakis, D. & Papachristodoulou, G. (1972) *Research on Attitudes and Behaviour of the Public towards Cancer*. Athens.
- Sarsby, J. (1984) *Ethnographic Research*, London: Academic Press.
- Saunders, Y. & Baines, M. (1983) *Living with Dying. The Management of Terminal Disease*, Oxford: Oxford University Press.
- Savage, J. (1995) *Nursing Intimacy. An Ethnographic Approach to Nurse-Patient Interaction* Harrow: Scoutari Projects Ltd.
- Savage, J. (2000) Ethnography and health care. *British Medical Journal*, **321**(7273), 1400.

-
- Schell, J.O. & O'Hare, A.M. (2013) Illness trajectories and their relevance to the care of adults with kidney disease. *Current Opinion in Nephrology and Hypertension*, **22**(3) 316-24
- Schensul, S. L., Schensul, J. J. & LeCompte, M. D. (1999) *Essential Ethnographic Methods: Observations, Interviews, and Questionnaires*, Walnut Creek: Altamira Press.
- Schneider, E.C., Malin, J.L., Kahn, K.L., Ko, C.Y., Adams, J. & Epstein, A.M. (2007) Surviving colorectal cancer. *Cancer*, **110**(9), 2075-82.
- Schwandt, T.A. (2001) *Dictionary of Qualitative Inquiry*, London: SAGE.
- Seale, C. (1991) Communication and awareness about death: a study of a random sample of dying people. *Social Science & Medicine*, **32**(8), 943-52.
- Seale, C., Addington-Hall, J. & McCarthy, M. (1997) Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine*, **45**(3), 477-84.
- Seale, C. (1998) *Constructing Death. The Sociology of Dying and Bereavement.*, Cambridge: Cambridge University Press.
- Sepúlveda, C., Marlin, A., Yoshida, T. & Ullrich, A. (2002) Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*, **24**(2) 91-6.
- Seremetakis, C. N. (1991) *The Last Word: Women, Divination and Death in Inner Mani*, Chigaco: University of Chicago Press
- Seymour, J. (2007) Ethnography. In Julia M Addington-Hall, J. M., Bruera, E., Higginson, I. J & Payne S. (eds.) *Research Methods in Palliative Care*, Oxford: Oxford University Press
- Shaul, M.P. (1997) Transitions in chronic illness: rheumatoid arthritis in women. *Rehabilitation Nursing*, **22**(4), 199-205.
- Shih, C.Y., Hu, W.Y., Lee, L.T., Yao, C.A., Chen, C.Y. & Chiu, T.Y. (2013) Effect of a compassion-focused training program in palliative care education for medical students. *The American Journal of Hospice & Palliative Care*, **30**(2), 114-20.
- Sholevar, G.P. & Perkel, R. (1990) Family systems intervention and physical illness. *General Hospital Psychiatry*, **12**(6), 363-72.
- Silverstone, R. (1994) *Television and Everyday Life*, London: Routledge.
- Singer, P. A., Martin, D. K. & Kelner, M. (1999) Quality end-of-life care: patients' perspectives. *The Journal of the American Medical Association*, **281**(2) 163-8.
- Skeggs, B. (2001) Feminist ethnography. In Atkinson, P., Coffey, A., Delamont, S., Lofland, J. and Lofland, L. (eds.) *Handbook of Ethnography*, 426-42.
- Smith, R. (2000) A good death. An important aim for health services and for us all. *British Medical Journal*, **320**(7228) 129-30.
- Smith, A.K., Buss, M.K., Giansiracusa, D.F. & Block, S.D. (2007) On being fired: experiences of patient-initiated termination of the patient-physician relationship in palliative medicine. *Journal of Palliative Medicine*, **10**(4), 938-47.

-
- Soenen, R. (2002) Diversity as a perspective for ethnography: from a 'critical' child to an ethnographer with little experience, in Walford, J. (ed.) *Debates and Developments in Ethnographic Methodology*, Oxford: Elsevier Science.
- Spall, B., Read, S. & Chantry, D. (2001) Metaphor: exploring its origins and therapeutic use in death, dying and bereavement. *International Journal of Palliative Nursing*, **7**(7), 345-53.
- Spencer, J. (2001) Ethnography after postmodernism. In Atkinson, P., Coffey, A., Delamont, S., Lofland, J. and Lofland, L. eds.) *Handbook of Ethnography* London: SAGE.
- Spiridakis, G. K. (1972) *Greek folklore. Popular culture of modern Greeks. Volume C (social life)* Athens: University of Athens.
- Spradley, J. P. (1980) *Participant Observation*, 1st. New York: Holt, Rinehart and Wilson.
- Stajduhar, K.I. (2003) Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, **19**(1), 27.
- Staton, J., Shuy, R.W. & Byock, I. (2001) *A Few Months to Live: Different Paths to Life's End*, Washington, D.C.: Georgetown University Press.
- Stefanou, N. & Faircloth, S. (2010) Exploring the concept of quality care for the person who is dying. *British Journal of Community Nursing*, **15**(12), 588-93.
- Steinhauser, K., Clipp, E. & Tulsky, J. (2002) Evolution in measuring the quality of dying. *Journal of Palliative Medicine*, **5**, 407-14.
- Steinhauser, K. E. (2005) Measuring end-of-life care outcomes prospectively. *Journal of Palliative Medicine*, **8** (Suppl 1) S30-41.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L. & Tulsky, J. A. (2000a) Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *The Journal of the American Medical Association*, **284**(19) 2476-82.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M. & Tulsky, J. A. (2000b) In Search of a Good Death: Observations of Patients, Families, and Providers. *Annals of Internal Medicine*, **132**(10) 825-32.
- Stiefel, F. & Senn, H. J. (1992) Cancer diagnosis disclosure in a Spanish hospital: how do they discuss treatment options? *Annals of oncology*, **3**(6) 422.
- Stobaei, I. (1536) *Collectiones Sententiarum, Speech 185 about death*, Barholomaei Zanetti Casterzagensis, Venetii, (Online) Available: <http://invenio.lib.auth.gr/record/127221/files/005.pdf?version=1> (Assessed October 2012)
- Strang, S. & Strang, P. (2001) Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliative Medicine*, **15**(2), 127-34.
- Strang, P., Strang, S., Hultborn, R. & Arner, S. (2004) Existential pain--an entity, a provocation, or a challenge? *Journal of Pain and Symptom Management*, **27**(3) 241-50.
- Strauss, A. & Corbin, J. (1990) *Basics of Qualitative Research*, London: Sage.
- Surbone, A. (1993) The information to the cancer patient: psychosocial and spiritual implications. *Supportive Care in Cancer*, **1**(2) 89-91.

-
- Sutton, D. (2004) Ritual, Continuity and Change: Greek reflections. *History and Anthropology*, **15**(2) 91-105.
- Tallman, K., Greenwald, R., Reidenouer, A. & Pantel, L. (2012) Living with advanced illness: longitudinal study of patient, family, and caregiver needs. *The Permanente journal*, **16**(3), 28-35.
- Tassinari, D. (2003) Surrogate end points of quality of life assessment: have we really found what we are looking for? *Health Qual Life Outcomes*, **1**, 71.
- Tay, L.H., Hegney, D. & Ang, E. (2011) Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. *International Journal of Evidence-Based Healthcare*, **9**(2), 151-64.
- Teno, J. M., Byock, I. & Field, M. J. (1999) Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life-limiting illness. *Journal of Pain and Symptom Management*, **17**(2) 75-82.
- Teno, J. M., Casey, V. A., Welch, L. C. & Edgman-Levitan, S. (2001a) Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members. *Journal of Pain and Symptom Management*, **22**(3) 738-51.
- Teno, J.M., Weitzen, S., Fennell, M.L. & Mor, V. (2001b) Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *Journal of Palliative Medicine*, **4**(4), 457-64.
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R. & Mor, V. (2004) Family perspectives on end-of-life care at the last place of care. *The Journal of the American Medical Association*, **291**(1) 88-93.
- The, A.M. (2002) *Palliative Care and Communication, Experiences in the Clinic*, Buckingham: Open University Press.
- Thome, B., Esbensen, B. A., Dykes, A. K. & Hallberg, I. R. (2004) The meaning of having to live with cancer in old age. *European Journal of Cancer Care*, **13**(5) 399-408.
- Tilden, L.B., Williams, B.R., Tucker, R.O., MacLennan, P.A. & Ritchie, C.S. (2009) Surgeons' attitudes and practices in the utilization of palliative and supportive care services for patients with a sudden advanced illness. *Journal of Palliative Medicine*, **12**(11), 1037-42.
- Tobin, G. A. & Begley, C. M. (2004) Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, **48**(4) 388-96.
- Toohey, P. (2010) Death and Burial in the Ancient World in Gagarin, M., & Fantham, E. (Eds.) *The Oxford Encyclopaedia of Ancient Greece and Rome* Oxford University Press.
- Triantafillidis, M., (1965) *Dictionary of The Common Modern Greek*; (Online) Available: <http://www.greek-language.gr/greekLang/index.html> (Assessed January 2012)
- Vachon, M.L.S. (2010) The emotional problems of the patient in palliative medicine. In Hanks, G., Cherny, N. I., Christakis, N. A., Fallon, M., Kaasa, S. and Portenoy, R. K. (eds.) *Oxford Textbook of Palliative Medicine* Oxford, New York, pp. 1410-36.
- Vadalouca, A. (2009) HSPSCCNCP: foster palliative care and pain management in Greece. *European Journal of Palliative Care*, **16**(5) 256-8.

-
- Vadalouca, A., Siafaka, I. & Argyra, E. (2006) Development of a care programme for older people. *European Journal of Palliative Care*, **13**(5) 214-5.
- Van Maanen, J. & Kolb, D. (1985) The professional apprentice: A comparative treatment of ethnographic roles, in Bacharach, S. (ed.) *New Perspectives in Organizationul Sociology* Greenwich, CT: JAI Press.
- Van Staa, A.L., Visser, A. & van der Zouwe, N. (2000) Caring for caregivers: experiences and evaluation of interventions for a palliative care team. *Patient Education and Counseling*, **41**(1), 93-105.
- Vasiliev, A. A. (1952) *The History of the Byzantine Empire*, 2nd ed. Madison: University of Wisconsin Press.
- Ventafridda, V., Ripamonti, C., De Conno, F., Tamburini, M. & Cassileth, B. R. (1990) Symptom prevalence and control during cancer patients' last days of life. *Journal of Palliative Care*, **6**(3) 7-11.
- Vidalis, A., Dardavessis, T. & Kaprinis, G. (1998) Euthanasia in Greece: moral and ethical dilemmas. *Aging (Milano)*, **10**(2) 93-101.
- Volker, D.L. (2005) Control and end-of-life care: Does ethnicity matter? *American Journal of Hospice and Palliative Medicine*, **22**(6), 442-6.
- von Gunten, C. F. (2002) Secondary and tertiary palliative care in US hospitals. *The Journal of the American Medical Association*, **287**(7) 875-81.
- Voultsos, P., Njau, S. N. & Vlachou, M. (2010) The issue of euthanasia in Greece from a legal viewpoint. *Journal of Forensic and Legal Medicine*, **17**(3) 131-6.
- Walter, T. (2003) Historical and cultural variants on the good death. *British Medical Journal*, **327**, 218-220.
- Waddington, D. (1994) Participant observation, in Cassell, C. & Symon, G. (eds.) *Qualitative Methodology in Organizational Research: a Practical Guide*, London: Sage.
- Wade, D.T. & Halligan, P.W. (2004) Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, **329**(7479), 1398.
- Wagner, G.J., Riopelle, D., Steckart, J., Lorenz, K.A. & Rosenfeld, K.E. (2010) Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *Journal of Pain and Symptom Management*, **39**(3), 527-34.
- Ware, N. C., Tugenberg, T., Dickey, B. & McHorney, C. A. (1999) An Ethnographic Study of the Meaning of Continuity of Care in Mental Health Services. *Psychiatric Services*, **50**(3) 395-400.
- Weaver, S.J., Lyons, R., DiazGranados, D., Rosen, M.A., Salas, E., Oglesby, J., Augenstein, J.S., Birnbach, D.J., Robinson, D. & King, H.B. (2010) The anatomy of health care team training and the state of practice: a critical review. *Academic Medicine* **85**(11), 1746-60.
- Werth, J.L. & Blevins, D. (2009) *Decision-Making Near the End-Of-Life*, Routledge, New York.
- WHO. (1990) *Cancer pain relief and palliative care. Report of a WHO Expert Committee* Geneva WHO.

-
- WHO. (2002) *National cancer control programmes: policies and managerial guidelines. Pain Relief and Palliative Care*. Geneva: 84.
- Wilde, V. (1992) Controversial Hypotheses on the Relationship between Researcher and Informant in Qualitative Research. *Journal of Advanced Nursing*, **17**(2), 234-42.
- Willis, J. (ed.) (2007) *Foundations of Qualitative Research: Interpretive and Critical Approaches*, California: Sage Publications Ink.
- Wiseman, T. (2002) *An Ethnographic Study of the Use of Empathy on an Oncology Ward*, PhD thesis, Manchester University
- Wolcott, H. F. (1995) *The Art of Fieldwork*, Walnut Creek: Altamira Press.
- Wolcott, H. F. (1999) *Ethnography- a Way of Seeing*, California: Alta Mira Press.
- Wright, L.M. & Leahey, M. (2005) The three most common errors in family nursing: how to avoid or sidestep. *Journal of Family Nursing*, **11**(2), 90-101.
- Yedidia, M. J. & MacGregor, B. (2001) Confronting the prospect of dying. reports of terminally ill patients. *Journal of Pain and Symptom Management*, **22**(4) 807-19.
- York, S. (2000) *Remembering Well: Rituals for Celebrating Life and Mourning Death*, San Francisco, California: Jossey-Bass.

13. Appendices

Appendix 1: Supporting letter from supervisors at King's College London

**Florence Nightingale
School of Nursing
and Midwifery**

Chair in Cancer and Palliative
Nursing Care
**Professor Alison
Richardson**

5th Floor, Waterloo Bridge Wing
Franklin Wilkins Building
150 Stamford Street
London SE1 9NH
Telephone +44 (0)20 7848 3503
Fax +44 (0)20 7848 3764
Email: Alison.Richardson@kcl.ac.uk

For the attention of Dr Mertikopoulos
Chairman of the Scientific Committee of the 'Agios Savvas' Hospital

6th December 2005

Dear Dr Mertikopoulos

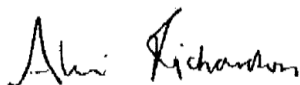
Re: Consideration of proposal by Ms Despina Anagnostou to conduct doctoral research at Agios Savvas Hospital

We are very pleased to hear that you are giving your attention to the proposal by Ms Anagnostou to undertake her data collection for her PhD within your hospital and that the Scientific committee will very soon be in a position to inform us of their opinion as to whether permission will be given for her to proceed. We believe you now have all the necessary paperwork with which to make an informed decision. You will appreciate that a decision on this matter as soon as possible would be extremely helpful.

For your information, the supervisory team consists of 3 individuals who the University has judged bring the necessary expertise to ensure a successful and quality outcome. This team consists of myself, a Professor of Cancer and Palliative Nursing, Professor Irene Higginson, a palliative care physician and public health doctor, and Dr Theresa Wiseman a nurse with particular expertise in qualitative research methods.

We appreciate the time and care you are personally giving to Ms Anagnostou's case. We look forward to hearing the outcome of the deliberations of the committee and very much hope they will wish to support this study. Please thank them for the contribution they are making to help ensure a quality piece of work is conducted.

Yours sincerely



Alison Richardson
Chair of Cancer and Palliative Nursing Care

On behalf of Ms Anagnostou's supervisory team at King's College London

Appendix 2: Application and approval letter from hospital Scientific Committee and information sheet for health professionals

ΠΡΩΤΟΚΟΛΛΟ ΕΡΕΥΝΑΣ

ΘΕΜΑ: «ΜΙΑ ΕΘΝΟΓΡΑΦΙΚΗ ΜΕΛΕΤΗ ΤΗΣ ΦΡΟΝΤΙΔΑΣ ΑΣΘΕΝΩΝ ΜΕ ΚΑΡΚΙΝΟ ΣΕ ΠΡΟΧΩΡΗΜΕΝΟ ΣΤΑΔΙΟ». Η έρευνα θα κατατεθεί ως διδακτορική διατριβή και θα διεξαχθεί ταυτόχρονα στην Ελλάδα και Μ. Βρετανία.

ΑΙΤΙΑ ΑΝΑΛΗΨΗΣ ΘΕΜΑΤΟΣ: Η φροντίδα ασθενών με καρκίνο και μάλιστα σε προχωρημένο στάδιο έως και τελικό ήταν ανέκαθεν καθήκον για τους περισσότερους επιστήμονες υγείας. Ωστόσο, μόλις τις τελευταίες δεκαετίες οι ανάγκες αυτών των ασθενών επισημάνθηκαν ως εξειδικευμένες (WHO 1990). Η ειδικότητα παρηγορητικής αγωγής ιδρύθηκε με στόχο την βελτίωση της ποιότητας ζωής των ασθενών και των οικογενειών τους που αντιμετωπίζουν ασθένεια που απειλεί τη ζωή τους (life-threatening illness), μέσω της έγκαιρης αναγνώρισης, αξιολόγησης και θεραπείας του πόνου και άλλων προβλημάτων: σωματικών, ψυχο-κοινωνικών και πνευματικών.

Έκτοτε η κλινική πράξη καθώς και η αντίστοιχη έρευνα επικεντρώθηκε στην διερεύνηση των αναγκών και στην παροχή ολιστικής φροντίδας για τους ασθενείς με προχωρημένη νόσο. Παρά τον προσανατολισμό της έρευνας στην εμπειρία της ασθένειας, την ποιότητα ζωής και φροντίδας των ασθενών με προχωρημένη νόσο, υπάρχει έλλειψη έρευνας που ακολουθεί τους ασθενείς κατά την πορεία της νόσου. Αυτό είναι αρκετά ανησυχητικό δεδομένης της παραδοχής ότι οι ανάγκες, οι επιθυμίες και προτιμήσεις αυτών των ασθενών αλλάζουν καθώς εξελίσσεται η νόσος, ειδικά όταν πλησιάζει το τέλος της ζωής τους (Doyle 1999). Πιθανόν η αδυναμία παρακολούθησης αυτών των αλλαγών να σχετίζεται με την καταγραφή μειωμένης ικανοποίησης των ασθενών και των οικογενειών τους από την παρεχόμενη φροντίδα (Gagnon 2005; Bostrom et al 2004). Παράλληλα στο περιοδικό European Journal of Cancer δημοσιεύτηκε ότι ενώ υπάρχει

δυνατότητα να ανακουφιστεί το 75-80% των ασθενών που υποφέρουν, τελικά μόνο το 10% ανακουφίζεται (Hanks 1995).

Η συγκεκριμένη μελέτη, κατά συνέπεια, προτείνει μια prospective- longitudinal εθνογραφική προσέγγιση της φροντίδας αυτής της κατηγορίας ασθενών, καθώς και της προσωπικής τους εμπειρίας της ασθένειας και της παρεχόμενης σε αυτούς φροντίδας. Η μελέτη αυτή, ελπίζει να συμβάλλει στην βιβλιογραφία διερευνώντας την καθημερινότητα (everyday life) των ασθενών με καρκίνο σε προχωρημένο στάδιο, να αναγνωρίσει μηχανισμούς με τους οποίους αλλάζουν οι ανάγκες και επιθυμίες αυτών των ασθενών και να ανιχνεύσει εκείνους τους πολιτιστικούς παράγοντες που είναι σημαντικοί για την διαμόρφωση της κατάλληλης φροντίδας.

ΥΛΙΚΟ ΚΑΙ ΜΕΘΟΔΟΣ: Η Το δείγμα της έρευνας θα αποτελείται από περίπου 100 συμμετέχοντες: ασθενείς, μέλη της οικογένειας τους και τους γιατρούς και νοσηλευτές εμπλεκόμενους στην φροντίδα τους. Παρόλο που η έρευνα επικεντρώνεται στους ασθενείς με καρκίνο, θα συμπεριληφθούν μέλη της οικογένειας των ασθενών καθώς και οι εμπλεκόμενοι επιστήμονες υγείας στην φροντίδα τους, ώστε να αποκτηθεί μια ευρύτερη αντίληψη γύρω από το πολύπλοκο φαινόμενο της φροντίδας ασθενών με καρκίνο σε προχωρημένο στάδιο. Η μέθοδος συλλογής δεδομένων θα είναι η συμμετοχική παρατήρηση και η ημι-δομημένη συνέντευξη με κλειστές και ανοικτές ερωτήσεις. Η συνέντευξη θα καταγράφεται ανώνυμα. Επίσης μέσο συλλογής δεδομένων θα αποτελέσουν ο ιατρικός φάκελος και τα νοσηλευτικά δελτία ασθενών.

ΕΙΔΟΣ ΕΡΕΥΝΑΣ: Η έρευνα θα ακολουθήσει ποιοτική εθνογραφική προσέγγιση. Πρόκειται για διερευνητική, προοπτική μη πειραματική μελέτη. Η εθνογραφική προσέγγιση επιλέχτηκε ως η πιο αποτελεσματική μέθοδος, για τους εξής λόγους :

- Επικεντρώνεται στην ανθρώπινη συμπεριφορά όπως αυτή εκδηλώνεται στην καθημερινή πραγματικότητα και όχι σε μη φυσικά, πειραματικά περιβάλλοντα δημιουργηθέντα για ερευνητικούς σκοπούς.

- Μπορεί να συνδυάσει πολλές τεχνικές συλλογής δεδομένων, αλλά κυρίως στηρίζεται στην συμμετοχική παρατήρηση και την συνέντευξη
- Η συλλογή δεδομένων μέσω της εθνογραφικής ποιοτικής έρευνας έχει την ευελιξία να αποφεύγει προκαθορισμένες υποθέσεις οι οποίες μπορούν να επιβάλλουν κατευθύνσεις στις απόψεις των συμμετεχόντων
- Δίνεται η δυνατότητα στους συμμετέχοντες να διευκρινίζουν το περιεχόμενο των λόγων, αποφάσεων και πράξεών τους.

ΖΗΤΗΜΑΤΑ ΗΘΙΚΗΣ: Η έρευνα δεν περιλαμβάνει σε οποιαδήποτε περίπτωση κανενός είδους παρέμβαση ή πειραματισμό σε ανθρώπους. Για την διεξαγωγή της θα ζητηθεί πληροφορημένη συγκατάθεση. Θα ζητηθεί έγγραφη συγκατάθεση των συμμετεχόντων αφού έχουν πρώτα ενημερωθεί για το περιεχόμενο και τους στόχους της έρευνας.

Επειδή στην Ελλάδα πολύ συχνά οι ασθενείς δεν γνωρίζουν την διάγνωση και πρόγνωσή τους, το ενημερωτικό φυλλάδιο για τους συμμετέχοντες δεν θα περιέχει τις λέξεις καρκίνος και νόσο τελικού σταδίου αλλά σοβαρή νόσος με πιθανόν χρόνιες παρενέργειες.

Θα τονιστεί στους συμμετέχοντες ότι μπορούν να παραιτηθούν από την έρευνα οποιαδήποτε στιγμή το θελήσουν, χωρίς την υποχρέωση να καταθέσουν οποιαδήποτε εξήγηση.

Η ιδιωτικότητα (privacy), η αξιοπρέπεια και ο σεβασμός των συμμετεχόντων είναι κύριο μέλημα του ερευνητή. Ο ερευνητής λαμβάνει υπ όψιν ότι πρέπει να διαθέτει την ευαισθησία να αποσύρεται όταν αυτό επιβάλλουν οι περιστάσεις και όταν το ζητούν οι συμμετέχοντες.

Ο ερευνητής δεσμεύεται να διαφυλάξει την ανωνυμία των συμμετεχόντων και να τηρήσει εχεμύθεια εκείνων των δεδομένων που οι συμμετέχοντες επιθυμούν να μην κοινοποιηθούν.

Βασική ηθική υποχρέωση είναι η προστασία των συμμετεχόντων από οποιαδήποτε σωματική, ψυχική ή οικονομική βλάβη.

ΤΟΠΟΣ ΚΑΙ ΧΡΟΝΟΣ ΔΙΕΞΑΓΩΓΗΣ ΕΡΕΥΝΑΣ: Αντικαρκινικό Ινστιτούτο Άγιος Σάββας.
Η διάρκεια της έρευνας υπολογίζεται σε 12 μήνες.

ΦΟΡΕΑΣ ΥΛΟΠΟΙΗΣΗΣ ΤΗΣ ΜΕΛΕΤΗΣ: King's College London, Department of Nursing,
Chair of Cancer and Palliative Nursing Care

ΥΠΕΥΘΥΝΟΣ ΚΑΘΗΓΗΤΗΣ: Alison Richardson, Irene Higginson

ΑΤΟΜΙΚΑ ΣΤΟΙΧΕΙΑ ΕΡΕΥΝΗΤΗ:

Όνομα: Δέσποινα Αναγνώστου

Διεύθυνση: xxxxxxxxxxxxxxxxx, Αθήνα

Τηλέφωνο επικοινωνίας: xxxxxxxxxxxxxxxxx

ΠΑΡΑΠΟΜΠΕΣ

Bostrom B, Sandh M, Lundberg D, Fridlund B (2004) Cancer-related pain in palliative care: patients' perceptions of pain management. *Journal of Advanced Nursing* 45(4):410-9

Doyle D (1999) *The platform ticket: memories and musings of a hospice doctor*
Durham: The Pentland Press

Gagnon E (2005) Facets of patient complaints: pain, suffering, and the importance of consideration *Med Sci* 21(6-7):648-51

Hanks GW (1995) Problem areas in pain and symptom management in advanced cancer patients. *European Journal of Cancer* 31:869-70

World Health Organisation (1990) *Cancer pain relief and palliative care* Geneva: Technical Report Services 804 WHO

ΕΠΙΣΥΝΑΠΤΟΝΤΑΙ

1. Η έγκριση της επιτροπής ηθικής και δεοντολογίας του πανεπιστημίου στο πρωτότυπο
2. Γράμμα της επιβλέπουσας καθηγήτριας προς την επιστημονική επιτροπή του νοσοκομείου



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
ΥΠΟΥΡΓΕΙΟ ΥΓΕΙΑΣ & ΚΟΙΝ. ΑΛΛΗΛΕΓΓΥΗΣ
ΕΘΝΙΚΟ ΣΥΣΤΗΜΑ ΥΓΕΙΑΣ

ΑΝΤΙΚΑΡΚΙΝΙΚΟ-ΟΓΚΟΛΟΓΙΚΟ ΝΟΣΟΚΟΜΕΙΟ
ΑΘΗΝΩΝ «Ο ΑΓΙΟΣ ΣΑΒΒΑΣ» Ν.Π.Δ.Δ.

Α/νση: Λεωφ. Αλεξάνδρας 171 – 115 22 ΑΘΗΝΑ
Τηλ: 210 64 09 000, Fax: 210 64 20 146

Δ/νση Διοικητικού – Οικονομικού
Υποδιεύθυνση Διοικητικού
Τμήμα : Προσωπικού
Πληροφ. : Ε. Ζερβοπούλου
Τηλ. : 210 – 64 09 128
Fax : 210 – 64 20 146
e-mail : grammateia@agsavvas-hosp.gr

Αθήνα, 13 – 12 – 2005

Αρ. Πρωτ. 14387 / Φ. 416

Προς

την κα. Αναγνώστου Δέσποινα

Παρέμιν

Θέμα : Αίτηση για διεξαγωγή έρευνας
Σχετ. : Η υπ' αριθμ. 14387/φ. 416/9-11-2005 αίτησή σας

Σε απάντηση της ανωτέρω σχετικής αιτήσεως, με την οποία αιτείσθε την άδεια διεξαγωγής έρευνας στα πλαίσια της διδακτορικής σας διατριβής, σας γνωρίζουμε ότι το Επιστημονικό Συμβούλιο ενέκρινε την έρευνα αυτή, υπό τον απαραίτητο όρο της διαφύλαξης των ευαίσθητων προσωπικών δεδομένων κατά τη διενέργεια και επεξεργασία των συνεντεύξεων

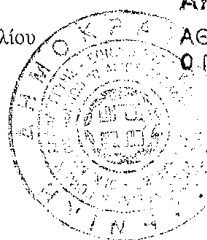
**Ο Διευθυντής Διοικητικής - Οικονομικής
Υπηρεσίας**

Ανδρέας Σιγάλας

Εσωτερική Διανομή

Πρόεδρο Επιστημονικού Συμβουλίου
Τ.Π.

Κ.Κ.



ΑΚΡΙΒΕΣ ΑΝΤΙΓΡΑΦΗ
ΑΘΗΝΑ 13/12/05
Ο ΠΡΟΪΣΤΑΜΕΝΟΣ ΓΡΑΜΜΑΤΕΙΑΣ α.α.

Βασιλική Κουρούση
ΒΑΣΙΛΙΚΗ ΚΟΥΡΟΥΣΗ

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Appendix 3: Details of each patient

Name	Gender	Age	Family status	Diagnosis	Point of recruitment	Date of death	Data collected
Con	Male	30	Not married- living with his parents and brother	Colorectal adenoma, st IV with lung and liver metastases	10 September 2006 HE was receiving chemotherapy, 6 th cycle of FOLFIRI	28 November 2006	Observation data: 100h interview data: 14h In the ward, and the coffee place of the hospital
Natasha	Female	37	Not married- living with her parents. Two older brothers Main carer: her parents	Cervical cancer with liver and lung, bone and brain metastases	2 September 2006 She was receiving chemotherapy	26 December 2006	Observational data: 137h Interview data: 9h In two wards and the A&E of another hospital
Maria	Female	40	Married with one child at the age of two	Breast cancer	26 April 2007	5 June 2007 she withdrew	I followed her for 2 months. Observation data: 40h Interview data: 3h
Giorgos	Male	41	Married, no children	LCLC	February 2007, he was receiving chemotherapy (most probably his 5 th cycle)	17 August 2007	5 months, in two wards, day care clinic, emergencies observation data 60h Interview data: 13h,

Pablo	Male	50	Married; two children Main carer: his wife and his sister in law	Small Cell Lung Cancer with liver, brain and bone secondaries	March 2007, after surgery of a hip fracture	30 Sept 2007	6, 5 months, + 2 retrospectively. Observation data: 67h Interview data: 29 h,
Ursula	Female	53	Not married; no children No main carer, occasionally some friends	Breast Cancer with bone metastases and heart failure	14 September 2005, while had one of chemo cycles, Andriamidine	20 January 2006 in private hospital	3 months (the last month only phone calls, as she left to North Greece) Observation data 40h, interview data 20h
Kula	Female	57	Married- not children Main carer: her husband, no other family	Cervical cancer with multiple peritoneal carcinomatosis	22 August 2006 She was receiving palliative treatment for her peripheral oedema and ascites	20 September 2006	Observation data: 35h interview data 3h
John	Male	60	Divorced; no family Main carer: occasionally a friend. Lately he hires private nurse assistants	Small-cell lung cancer with liver secondaries and dermatomyositis	31 August 2006 HE was receiving chemotherapy, 5 th cycle of Cisplatin/Vepesid Treatment for the dermatomyositis	21 February 2007	Observation data: 75h interview data 9h hours in two wards, the front yard of the hospital

Tamara	Female	65	Married, three children (24-28), one grandchild	Breast cancer, bone secondaries	25 May 2007 In an effort to unblock the chest catheter	16 June 2007	3 weeks at the same room Observation data: 39.5 h Interview data: 7.45h
Sila	Female	67	Married- not children Main carer: her sister and a niece	breast cancer (Lobular in Situ adenocarcinoma) with liver, lung and bone metastases	14 August 2006 She was having treatment for the ascites and chemotherapy: 2 nd cycle of CDDP and 5FU	15 October 2006	Observational data: 200h interview data: 13h in two wards, the day care clinic and at home
Mina	Female	70	Widow, one child (age 32) Main carer: sister and child	Ovarian cancer	3 May 2007 When chemotherapy was just terminated	15 June 2007	1 month, 10 days Observation data: 70h Interview data: 5h
Sotos	Male	72	Married, three children (25, 30, 34) 4 grandchildren Main carer: spouse and children in rotation	NHL	20 Feb 2007. He had chemotherapy	12 March 2007	1 month Observation data: 85h Interview data: 15 h
	Male	70	Married, two sons from his wife Main carer: his wife	Liver cancer	15 January 2007 he was in chemo: 5FU few stents placed due to jaundice, nausea	15 July 2007	6 months Observation data: 80h Interview data: 10h

Appendix 4: Interview topic guides

ΟΔΗΓΟΣ ΣΥΝΕΝΤΕΥΞΗΣ

Γενικές ερωτήσεις

Πώς βλέπετε τον ρόλο σας στην φροντίδα αυτών των ασθενών?

Με ποιο τρόπο πιστεύετε ότι βοηθάτε τους ασθενείς?

Με ποιο τρόπο συνεισφέρετε στην φροντίδα τους?

Ποιοι παράγοντες υποβοηθούν το έργο σας και ποιοι το δυσκολεύουν?

Τι νομίζετε ότι θα βοηθούσε το έργο σας και πώς νομίζετε ότι θα μπορούσαν να αντιμετωπιστούν οι τυχόν δυσκολίες?

Ποια είναι η γνώμη σας για την παρεχόμενη φροντίδα στους ασθενείς?

Είστε ικανοποιημένος /η από την εργασία σας?

Τι σας κάνει να παραμένετε στο χώρο αυτό? Πώς αισθάνεστε που φροντίζετε ασθενείς οι οποίοι το πιθανότερο είναι πως θα πεθάνουν από την ασθένεια τους?

Συνεργασία με συναδέλφους

Υπάρχουν άλλοι συνάδελφοι της ειδικότητας σας με τους οποίους συνεργάζεστε στο νοσοκομείο?

Με ποιο τρόπο ενημερώνετε για ασθενείς που χρειάζονται την δική σας παρέμβαση?

Ποιος αποφασίζει και παραπέμπει ασθενείς σε σας?

Πότε παραπέμπεται ασθενής σε σας?

Οι συνάδελφοι που σας καλούν έχουν ήδη διαγνώσει το πρόβλημα? Συμφωνείτε με τις εκτιμήσεις τους?

Καλείστε στον άρρωστο τη σωστή χρονική στιγμή που χρειάζεται, κατά την γνώμη σας?

Πώς βλέπετε (και είστε ικανοποιημένος) την συνεργασίας σας με άλλες ειδικότητες και επαγγέλματα? Ποιος ο ρόλος του νοσηλευτή στη συνεργασία αυτή?

Πιστεύετε πως η συνεργασία με άλλες ειδικότητες επηρεάζει την παρεχόμενη φροντίδα στον άρρωστο και πώς?

Ειδικές ως προς τον άρρωστο ερωτήσεις

Είστε αποδεκτός από τους ασθενείς? Πώς αντιμετωπίζουν το γεγονός ότι ένας ψυχίατρος τους έχει επισκεφτεί?

Μπορείτε να μου πείτε τις συνήθεις αιτίες που ένας άρρωστος παραπέμπεται σε σας? (Συνήθεις αιτίες στρες, κατάθλιψης)

Με ποιόν τρόπο παρεμβαίνετε? Πχ. Συμβουλευτικά, θεραπευτικά, συστηματική παρακολούθηση?

Κατά την εμπειρία σας, ποιες είναι οι συνήθεις αιτίες που ένας ασθενής οδηγείται σε κατάσταση που να χρήζει της παρέμβασής σας?

Υπάρχουν περιπτώσεις που οι θεράποντες γιατροί διαφωνούν με την παρέμβασή σας, αν ναι, πώς το χειρίζεστε?

Πόσο σημαντική θεωρείτε την συμμετοχή της οικογένειας στη δική σας παρέμβαση στον άρρωστο?

Υπάρχουν φορές που η οικογένεια του αρρώστου συμβάλει στην διαταραχή του ή παρεμποδίζει το δικό σας έργο, και πώς το χειρίζεστε?

Τι γνώμη έχετε για την ενημέρωση του ασθενή σε σχέση με την διάγνωση και κατάστασή του?

Έχουν ασθενείς προσπαθήσει να εκμαιεύσουν από εσάς την αλήθεια?

Έχετε κληθεί ποτέ να βοηθήσετε τον ασθενή ή την οικογένεια πλησιάζοντος του θανάτου?

Πιστεύετε πως έχετε ρόλο να παίξετε σε αυτήν την φάση?

Ποιος θάνατος είναι καλός κατά την άποψή σας? Παίζει ρόλο η επιλογή του τόπου θανάτου?

Ποια είναι η άποψή σας σε σχέση με την διαδικασία και τον τόπο θανάτου?

Appendix 5: Application and approval letter from King's College London Research Ethics Committee



For office use only:
 REC Protocol No
 Date rec'd:

APPENDIX 5: Application and approval letter from King's College London Research Ethics Committee

College Research Ethics Committee

APPLICATION FOR CREC APPROVAL

Please type in the grey boxes, which will expand automatically to encompass your text. Use the mouse or the tab key (with picture of two arrows, normally above the CAPS LOCK key) to move between the boxes. Remember that the application will have to be printed out, authorised, and then sent, with 17 copies, to the CREC office, Room 7.21 James Clerk Maxwell Building, Waterloo Campus, King's College London, 57 Waterloo Road, London SE1 8WA.

1. TITLE OF STUDY (guidance note 1)

An ethnographic study of the care of patients with advanced cancer: a Greek perspective

2. NATURE OF PROJECT (guidance note 2)

It will be an original PhD research study.

3. INVESTIGATORS (guidance note 3)

3a. Principal Investigator

Name: Alison Richardson

Post: Chair in cancer and palliative nursing care **Department:** Florence Nightingale School of Nursing and Midwifery

Qualifications: PhD, MSc, PGDE, BN (Hons), RN, RNT

Previous experience of Research on Human Subjects: Extensive experience in conducting and supervising nursing research over a period of 15 years involving both quantitative and qualitative methods. Over 20 funded projects.

3b. Other investigators / collaborators (please note their employer if other than King's College, London)

Despina Anagnostou, MSc, BSc (Hons), RN PhD student,

Professor Irene Higginson, Head of Department of Palliative Care and Policy Medicine 2nd supervisor

Dr Theresa Wiseman, RN, PhD, PGDE, BSc(Hons), RNT, RCNT, Lecturer in Cancer and Palliative Care, Florence Nightingale, School of nursing and midwifery, 3rd supervisor

4. PREFERRED TIMETABLE (guidance note 4)

4a. Preferred start date: September 2005

4b. Projected date of project's submission: December 2007

5. SPONSOR / OTHER ORGANISATIONS INVOLVED (guidance note 5)

KCL / Other institution (please circle)

If other:

5b. If your study involves another organisation, please provide details. Evidence that the relevant authority has given permission, i.e. a letter, is likely to be necessary.

Permission will be necessary from the Agios Savvas" Oncology Hospital in order to approach patients and health care professionals. When permission has been gained I will submit a letter of confirmation to CREC. With regard to outpatient appointments/consultations, the researcher is aware of the organisations that commonly care for patients. These will be approached and permission requested. Letters of permission to access these settings will be submitted when they become available.

6. OTHER REC APPROVAL (see introduction for guidance on when LREC approval is necessary)

6a. Has the proposed study been submitted to any other reviewing body? If so, please provide details.

Following College Research Ethics Committee approval, a submission will be made to the Agios Savvas" Oncology Hospital ethics committee in Greece. On receipt of approval the researcher will provide documentary evidence to CREC.

7. PURPOSE OF THE STUDY (guidance note 7)

Only recently have the needs of patients with a terminal illness been specifically recognised and addressed. Palliative Medicine was established in UK in 1987 and the World Health Organisation (WHO 1990) has defined palliative care as an approach to improve the quality of life of patients and their families facing a life-threatening illness by assessing and treating physical, psychosocial and spiritual problems.

Since then, palliative care research has focused on the needs and experiences of patients with life threatening illness (Carter et al 2004; Teno et al 2004; Murray 2000; Donely 1996). Even though it has been argued that patients' preferences, values and beliefs change during their illness trajectory and especially near the end of life (Doyle 1999; Singer et al 1998), only a number of studies have followed patients throughout their journey (Carter et al 2004; Thome et al 2004; Yedidia et al 2001). These studies have tried to understand the meaning that patients give to their illness or to their life with advanced cancer. A couple of studies have adopted a longitudinal approach (The 2002; Lawton 2001). These have proved fruitful in terms of how changes in the body and care influence patients' identity and life.

All the previous studies have been conducted in either the US or the UK. There is little evidence of the care and experiences of terminally ill patients in the rest of Europe. Yet, the National Council for Palliative Care (NCPC 2005) has declared that palliative care should be sensitive to cultural differences, and reflect the needs, values and health beliefs of different cultural groups. In addition, the International Association of Hospice and Palliative Care (IAHPC 2004) supports that each country should develop its own model of palliative care provision based on the needs of its local patients and its available resources, and not be expected to copy models from other countries with different socio-economic conditions.

In Greece specifically, where there is no institutionalised palliative care, little attention has been given to the needs of advanced cancer patients, either by the National Health System or health care researchers. There is no evidence of how

advanced cancer patients are cared for during the trajectory of their illness after the curative phase. The health care settings involved in the care of these patients, the kind of care provided and the health professionals' contribution and the role of families in care have not been explored. Moreover, no study exploring the nature and meaning of quality of life, the conception of the illness and the needs of terminally ill patients from the perspective of these patients have been conducted in Greece.

One way of studying people in their own settings is through Ethnography (Atkinson et al 2001; Brewer 2000). As ethnography represents an attempt to develop an understanding of a local world (Wiseman 2002) it will provide an understanding of the perceived experience in the specific context of the Greek health care system. This study attempts to explore the nature of care that such patients receive, to look into their quality of life and examine their experience of illness and care over time. This study hopes to contribute to the wider palliative care literature by exploring the *everyday life* of palliative care patients and identifying cultural issues important to palliative care in relation to the Greek context.

8. STUDY DESIGN, METHODOLOGY AND DATA ANALYSIS (guidance note 8)

Overall approach

This study will employ a qualitative approach using an ethnographic methodological framework. The reason for considering ethnography as the appropriate method is that it is concerned with:

1. People's behaviour in everyday contexts rather than under unnatural or experimental circumstances created by the research
2. Data are collected by various techniques but primarily by means of participant observation
3. Data collection is flexible and unstructured to avoid pre-fixed assumptions that impose categories on what people say and do
4. It is possible to clarify meanings of the participants throughout the research process

Setting

As there is no institutionalised palliative care in Greece, there are no specific services or settings providing care for patients who have reached the palliative phase of their illness. Therefore, these patients are cared for in several different settings and tend to move between different doctors, hospitals and clinics on numerous occasions. Initially, participants will be approached and recruited via an oncology hospital at the time their curative treatment ends and from this they will be followed through subsequent appointments and admissions. This method has been employed by Kelly (2002) to capture the experiences of a group of men with prostate cancer with much success.

Sources of data

Whilst patients are the primary focus of this study their families and health professionals involved in their care will also be involved, in order to gain a rounded perspective of the complex phenomenon of the care of patients with advanced cancer. Participant observation, formal and informal interviews and documents, such as patients' medical records and ward communication notes will be considered as the means of data collection. These methods have been employed in a number of ethnographic studies before in order to gain broader perspective of phenomenon, achieve a holistic view and enhance credibility of the findings (The 2002; Wiseman 2002; Lawton 2001).

Participant observation

Participant observation will be conducted over a period of 12 months. This will involve observing patients each time they enter a health care setting. It may also involve being present at home. Families and health care professionals involved in their care will be also observed. As this involves a number of types of participants, the researcher will ensure that all parties are aware of the research and are aware that data collection will involve only those who have consented to participate. This is common practice within ethnography (Wiseman 2002; Savage 1995). Participant observation requires the researcher to develop a role while being involved in everyday activities (Atkinson et al 2001). The researcher will take the role of an assistant on the ward or the outpatient clinic at the beginning of the study whilst recruiting patients from the oncology hospital. This role of assistant or volunteer has been adopted in prior studies (Lawton 2001; Wiseman 2002) so that the researcher can observe practice and clarify understanding of primary data collected. Later on, the researcher will adopt the role of companion as she follows patients to different settings – this might include appointments at outpatient clinics, doctors' offices and admission to a further hospital. This will enable her to explore patients' care and document different components of the Greek Health Care System. Moreover, this will offer the opportunity to trace the everyday life of these patients and understand their experience of care and illness. Observation will conclude before the patient approaches death and the appropriateness of the moment to do this will be led by the patient and family. The optimum length of observation will become more apparent as the study unfolds, though will typically be 2-4 hours when patients are in-patients or at home. In the case of outpatient consultation, the researcher will accompany the patient for the duration of the appointment if that is appropriate for the patient. A pilot

period of participant observation is planned in order to increase validity, consistency and rigour (Brewer 2000). Field notes will be recorded during periods of participant observation.

Interviews

Interviews will be conducted during the course of study. Patients, families and health professionals will be interviewed. Informal interviews will be used to clarify context during the participant observation. Written notes will be used to document these brief informal interviews. Formal interviews will be semi structured based on themes that emerge from the participant observation. Semi structured interviews will be used with the aim of exploring participants' perceptions, feelings, thoughts and decisions. They will also help clarify any discrepancies in attitudes and reality as well as covering topics noted to occur in the observational data. Formal interviews will be tape recorded and transcribed and the transcriptions shown to participants for further clarification (Wiseman 2002). It is anticipated that no more than one-two episodes of formal interviews per informant will be undertaken.

Data analysis

Preliminary data analysis will occur concurrently with data collection, following common practice within ethnography. The method known as Ethnographic Content Analysis will be used (Altheide 1996).

9. ETHICAL CONSIDERATIONS (guidance note 9)

As it is most common in Greece for patients not to acknowledge their diagnosis and prognosis, the information sheet will not include the words cancer or terminal illness, but instead use the term serious illness with possible chronic effects. Moreover, as the study will be longitudinal whilst consent will be gained at the start of data collection, it will be reconfirmed on ongoing basis with all participants during data collection (Wiseman 2002; Raudonis 1992). It will be stressed to participants that they can withdraw at any time and that confidentiality will be maintained. However, as the disease advances and patients approach the terminal stage of their illness it is anticipated that the researcher will withdraw – this will be a time when the utmost sensitivity to the needs and wishes of the both the patient and family will need to be deployed.

To secure privacy, dignity and respect (Polit & Beck 2004) during participant observation, the researcher will be sensitive to withdraw at times where her presence seems inappropriate, for example during the breaking bad news. It will be made clear to all participants that they can ask the researcher to leave if they feel her presence inappropriate, or interrupt the interview. If there is any doubt over whether patients or families are uncomfortable with the researchers presence at any time she will withdraw.

During participant observation, if there is a case where the patient is considered to be at an immediate risk, the researcher will cease her role in order to help (Bowling 2002). As the researcher is also a nurse she will be guided by her professional code of conduct at this time. Discussions with researchers with extensive experience using ethnographic methods indicate this is an extremely unlikely event.

As families and health care workers will be involved in the study, the researcher will seek their consent in order to include them. If they do not wish to participate, the researcher will exclude them from the data collection process. If family members decline to be involved it is very likely that patients will not be involved as in the Greek context families have the responsibility for the patient's care and they often take the decisions for them.

As far as is practical oral consent of all health care professionals in a particular setting will be obtained prior to them being involved in observation. The small number of staff involved each time, will mean those who don't wish to participate will be easily identified.

For the safety of the researcher, when and if she will visit patients at their homes, she will always inform an individual about the place she is going to be and her mobile phone number. A different mobile phone from that used as a personal number will be used for the purposes of the research and the participants will have access only to this number.

Due to the nature of this study, there will be times when data collection is likely to be emotionally draining for the researcher. The researcher will have an individual to whom she can turn to in Greece for support and

will also receive close supervision during the course of data collection from her 3rd supervisor, an experienced ethnographer and trained counsellor.

10. SUBJECTS TO BE STUDIED (guidance note 10)

MALE	FEMALE
<p>Number of volunteers: No more than 15 patients plus associated family members and health professionals. Their numbers cannot be specified at this moment.</p> <p>Upper age limit: none</p> <p>Lower age limit: 18</p>	

11. SELECTION CRITERIA (guidance note 11)

The sample size of this study will be approximately fifteen patients who are not receiving curative treatment and are diagnosed as having advanced cancer. Their families and key health professionals involved in their care will be also included. The researchers have included the following inclusion and exclusion criteria whilst determining the patients- sample of this study:

Inclusion criteria

- male and female, aged 18 years and over (for all participants)
- patients with advanced cancer
- not expected to survive beyond 12 months, but for greater than 3 months
- patients able to communicate and fully coherent at the starting point of the study

Exclusion criteria

- patients deemed unfit to participate by presiding consultant due to medical or psychological condition
- patients whose family do not agree to the terms of the study

12. RECRUITMENT (guidance note 12)

Patients

Identified:

Participants will be recruited from either an outpatient clinic or a ward of the “Agios Savvas” Oncology hospital. It is one of the three main oncology hospitals of Athens. The final decision on where the observation will commence will be made during June, when the researcher returns to Greece. Factors influencing the decision will be accessibility both to the setting and participants. Potential participants will be identified through discussions with clinical staff.

Approached:

Leaflets with information about the study will be hung on the notice boards of the settings involved. Potential patients and their families will receive first an introductory leaflet containing the information for the study (Appendix 4) from a member of the clinical team followed by an information sheet, if they indicate they are interested.

Recruitment:

The researcher will visit those who indicate they wish to participate and at this point will answer any questions they may have and give them the consent form. The researcher will collect the consent form the following day, after clarifying any potential questions (Appendix 2).

Families

Identified:

Patients will indicate to the researcher the family members that they consider to be their principal carer(s)

Approached:

The researcher will provide family members with the same information sheet as the patients and ask their consent to be observed and interviewed.

Recruitment:

Family members who consent, will be included in the sample of the study

Health care workers

Identified:

Nurses and doctors of the ward/clinic will be invited to a discussion on the project and to help define the role of the researcher as a participant observer (Appendix 3). Doctors and nurses involved in the care of the patients who are participants in the study will be included.

Approached:

First, meetings with the consultants and the ward managers will be requested in order that the researcher may inform them about the study. Further meetings with doctors and nurses who work in the ward or outpatient clinic will take place in order to discuss their possible participation.

Recruitment:

Health care workers, who will consent orally to observation, will be included in the sample of the study. Written consent will be necessary from those who will go on to be formally interviewed.

13. CONSENT (guidance note 13)

13a. How is consent to be obtained?

Participants will receive an information sheet before they decide to get involved in this study. Consent (Appendix 2) will be obtained from all participants at the beginning and ongoing oral consent will be requested throughout the study. To be more specific:

Patients' consent will be obtained in writing after providing them with the information sheet (Appendix 1) and perhaps further clarification discussions will have taken place.

Families will receive the same information sheet, as it is not possible to treat patients or make any decisions in relation to patients without their agreement in the Greek context. Otherwise, access and trust of participants will be jeopardised. Family members will give written consent in order to be observed and interviewed.

Health care workers in each setting that involves observation will be informed during the course of formal and informal meetings that will take place and information sheets provided (Appendix 3). Oral consent in order to be observed will be obtained. Those who will be key informants (those closely connected with each patients care) and hence involved in interviews will be asked to provide written consent (Appendix 2).

A copy of the participant information sheet and consent form must be attached to this application. For your convenience we have provided perform as at the end of this document. These should be filled in and modified where necessary and attached to the end of your application

13b. Will the participants be from any of the following groups? (Tick as appropriate.)

- Children under 18 ☐
- Children in care ☐
- Those with learning disability ☐
- Those suffering from dementia ☐
- Prisoners ☐
- Young Offenders (16-21 years old) ☐
- Those who could be considered to have a particularly dependent relationship with the investigator, eg those in care homes, medical students ☐
- Other vulnerable groups advanced cancer patients ☒

How will you ensure that participants in the groups listed above are competent to consent to take part in this study? *Please attach any correspondence to parents, guardians, carers, keyworkers etc.*

At the beginning of the study patients will be able to communicate and will be fully coherent. As they deteriorate, family members will consent on behalf of patients. There will be a time when it is inappropriate to continue observing the patient. The researcher will sensitively withdraw when this moment is reached.

13c. Are there any special pressures that might make it difficult for people to refuse to take part in the study (e.g. the potential participants are students or colleagues of the investigator)? How will you address this?

There are not thought to be any difficulties for people to refuse. The researcher is not a member of the health care team responsible for the care of patients involved in this study and has no previous encounters with the health care professionals.

14. PARTICIPANT'S INVOLVEMENT: RISKS, REQUIREMENTS AND BENEFITS (guidance notes 14)

14a. What are the potential hazards, risks or adverse effects associated with the study?

Though there are no physical risks or hazards associated with this study, there is a risk that the patient and their family may become reliant on or very attached to the researcher. The researcher will be conscious of this risk throughout the period of data collection and encourage the participants to continue to use their original means of support. It may be that the patient and their family are referred to counsellor as part of their care package. The researcher will encourage the patient and their family to use those agencies.

14b. Does your study involves invasive procedures such as blood taking, muscle biopsy or drug administration? No

If so, please provide details:

14c. Does your study involve genetic analysis or manipulation? No

If so, please provide details,

14d. Please list the experience of the investigators in the use of these procedures.

The research student has conducted interviews with cancer patients before, when participating in other projects. Up until this point the student has not had experience of participant observation as a data collection method. A pilot phase and regular ongoing supervision by telephone and face to face will help the research student to develop this approach.

14e. If medical devices are to be used on any subject, do they comply with the requirements of the Medical Devices Directives?

No medical devices will be used on any subject.

14f. Please describe how you would deal with any adverse reactions or untoward incidents.

In the event of the patient's safety being at risk, the researcher will be guided by her professional code of conduct.

14g. Please name the locations or sites where the work will be done (room number, etc.)

Hospital patients' rooms, out patient clinic rooms, health professional offices in "Agios Savvas" Oncology hospital and patients' homes

Further sites for observation will be identified during the course of the study, dependent on the 'journey' of each patient.

14h. Can women of child-bearing potential participate without significant risk? Yes

14i. Can lactating women participate without significant risk? Yes

14j. What is the potential for participants' suffering pain, discomfort, distress, inconvenience or changes to lifestyle as a result of participation?

It is possible that participants' (Patients, family members and health care professionals) may suffer some distress and inconvenience during their participation. The researcher will work hard to minimise this but it is not wholly preventable. It will be made clear to all those participating that they can withdraw at any time and have the right to ask the researcher to leave when observing them or stop interviewing them.

14k. Will group or individual interviews / questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting? If so, please list these topics and explain how you will prevent, or respond to, volunteer discomfort.

Participants may experience distress and anxiety at some point during data collection. Participants may feel embarrassed about the opinions they hold or choices they make. In order to avoid this, I will try to show them that I will not judge their actions and thoughts and values as they are all equally important and remain respectful at all times. If the interviews become intense, a debriefing session might be necessary to deal with some of the stress that participants might face. If they become significantly upset or distressed, the researcher may refer them to the hospital psychologist of the setting, after gaining the patient, carer or staff members consent.

14l. Is it possible that criminal or other disclosures requiring action (e.g. evidence of professional misconduct) could take place during the study? If yes, give details of what procedures will be put in place to deal with these issues. *The information sheet should make it clear under which circumstances action may be taken by the researcher.*

In the extremely unlikely event of the researcher witnessing unsafe practice or practice which has the potential to cause the patient severe harm or death, the researcher would have to intervene in accordance with her professional code of conduct. In this case, she will also contact the relevant authorities within the hospital. This would be a very rare occurrence which has never happened in the experience of any of the researchers.

14m. Please describe any expected benefits to the research participant.

No direct benefits are anticipated for the participants other than giving them the opportunity to express themselves and may through interviews experience catharsis for their distress and anxiety. The benefit will be for future patients and families if the study contributes to improving the care for this particular group.

14n. Under what circumstances might a participant not continue with the study, or the study terminated in part or as a whole?

In the case a participant wishes to withdraw or his-her family. The same goes for health care professionals. Observation will be discontinued as the patient approaches death and the appropriateness of the moment to do this will be led by the patient and family

15. FINANCIAL INCENTIVES, EXPENSES AND COMPENSATION (guidance note 15)

15a. Will travelling expenses be given? *If so, an appropriate comment should be included on the Information Sheet*

No

15b. Is any financial or other reward, apart from travelling expenses, to be given to participants? If yes, please give details and justification.

No

15c. Will the study result in financial payment or payment in kind to the department? Please specify, including the amounts involved.

No

15d. If this is a study in collaboration with a pharmaceutical company or an equipment manufacturer, please give the name of the company and indicate what arrangements exist for compensating patients or healthy volunteers for adverse effects resulting from their participation in the study (in most cases the Committee will only approve protocols if the pharmaceutical company involved confirms that it abides by ABPI guidelines). A copy of the indemnification form (appendix B) should be submitted alongside this application.

16. CONFIDENTIALITY, ANONYMITY AND DATA STORAGE (guidance notes 16 and 17)

What steps will be taken to ensure confidentiality? Give details of the anonymisation procedures to be used, and at what stage they will be introduced.

If participants request part of the data to be kept confidential and not used, the researcher will respect this. Participants' names will be not indicated and instead, pseudonym will be used when presenting the findings of the study. Only ID numbers will be recorded on the audiotapes.

Additional care will be taken in any written report or publication by not providing a full profile of the participants, in order that they are not identified. The specific setting in which the observation was undertaken will not be revealed in any publication, report or oral presentation.

The data will be kept in a closed, locked drawer and on the laptop of the researcher securing them with a password. The list of ID numbers and pseudonyms will be kept separately. Fieldnotes of participant

observation, tapes and their transcripts will be kept confidential to the researcher and the supervisory team. The tapes will be destroyed at the end of the study.

16b. Who will have access to the records and resulting data?

Only the research student and her supervisors

16c. Where, and for how long, do you intend to store the consent forms and other records?

The consent forms and other records will be kept in a locked cupboard in secure archives, for seven years under the management of the primary supervisor at King's College London.

17 INFORMATION SHEET AND CONSENT FORM (guidelines 17 and 18)

The information sheet for participants on the next page should be composed according to our guidelines and submitted alongside this protocol. You should also submit a copy of our standard consent form with the name of your project added. Details of how these documents should be used are provided in the guidelines.

The following, where applicable, are attached to this form (please tick):

- ☐ Participant Information Sheet
- ☐ Consent Form
- ☐ Appendix A relating to medical products
- ☐ Appendix B Certificate of Indemnity (for pharmaceutical company collaborators)
- ☐ Appendix C relating to studies involving radiation (available separately; request from CREC office)
- ☐ Letter to general practitioners
- ☐ Letter to parents/guardians/key carer/social services
- ☐ Letter of ethical committee approval or other approvals
- ☐ Copy of email recruitment circular/poster/press advertisement.

INFORMATION SHEET FOR PARTICIPANTS

REC Protocol Number.....

Appendix 1**Study: A study of the care of patients experiencing serious illness: A Greek perspective****Patients and families information sheet**

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. You have been given information about the study because you have been ill for a while now and you have been admitted to hospital several times in the past. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

The study has been funded by the Greek Government (by giving a scholarship to the researcher to study abroad) and is being led by the researcher in connection with King's College London where she studies. The King's College Ethics Committee and the "Agios Savvas" Oncology Hospital Ethics Committee have approved this information sheet. The approval numbers are...

The purpose of the study is to explore what care patients who experience a serious illness receive. The study aims to understand patients' perceptions of their needs and understand their experience of being seriously ill. It is also interested in exploring whether patients are satisfied with this care they receive and describe their everyday life and how it has been affected by their illness and the care they receive.

The researcher hopes to accompany you over the next 12 months when you have medical appointments or you are going to the hospital so that she can gain an understanding of what is happening to you and observe the care you receive. If you would like, she could visit you at home to see how your life is outside hospital. She is also interested in how you and your family cope with the situation and thus she asks permission from your family to observe them as well. She may take some notes during the time she is observing you.

The researcher also hopes to conduct some interviews with you and some family members, so that she can gain a better understanding of your opinions, thoughts and perspectives. Interviews will be taped and transcribed by the researcher to help her analyse them properly, and if you would prefer she could take notes instead. At any time you may ask for the tape to be stopped or for her to stop writing notes. There are no right or wrong answers, or bad and good opinions. Your own personal thoughts and feelings are of interest. Conversations during the time the researcher will be with you may also take place, particularly when she would like to clarify issues occurring from the observation.

We cannot promise that taking part in the study will be of direct benefit to you, but an important part of the study is to find out what patients think of their needs and the care they receive, so that the results from the study will help health professionals to determine more accurate and effective ways to help future patients.

Any information which is collected about you, or that you provide during the study, will be kept strictly confidential. The information we collect will have your personal details removed so that you

cannot be recognised by it. Information, including tape-recorded information, will be held securely for the period the study is carried out. The tapes will be destroyed at the end of the study and other information destroyed seven years after its completion.

When the findings have been analysed, they will be prepared for publication in nursing and medical journals, and for presentation at conferences. A summary of the results will be available for all study participants.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through King's College London's 'No Fault Compensation Scheme'.

Thank you for reading the information

The researcher will be happy to answer any questions you may have about this research study and can be contacted on the number...

Despina Anagnostou
Doctoral Research Student
King's College London

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Appendix 2

Participants Consent form

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: A study of the care of patients experiencing serious illness: a Greek perspective

King's College Research Ethics Committee Ref: _____

- Thank you for considering taking part in this research. The person organizing the research must explain the project to you before you agree to take part.
- If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.
- If you decide, now or at any other time during the research, that you do not wish to be involved in this project, just tell us and we will withdraw you from it.

Let us know if you are happy:

to be interviewed

☐

to be observed

☐

for us to look at your medical records

☐

Participant's Statement:

I _____

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

Investigator's Statement:

I _____

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the volunteer.

Signed

Date

AUTHORISING SIGNATURES

The information supplied above is to the best of my knowledge and belief accurate. I have read the notes to investigators and clearly understand my obligations and the rights of subjects/study participants, particularly in so far as to obtaining valid consent.

Signature of Principal Investigator

.....Date.....

Signature of Head of Department

.....Date.....

Signature of Medical Supervisor (if appropriate)

.....Date.....

Communications about this application should be addressed to:

Name: Despina Anagnostou

Address: (full postal address please)

Kings College London
Florence Nightingale School of Nursing and Midwifery
James Clerk Maxwell Building
Post graduate office
57 Waterloo Road
London SE1 8WA

Telephone No:

Fax No:

Email: despina.anagnostou@kcl.ac.uk

Appendix 3

Health Care Professional Information Sheet

Study: An ethnographic study of the care of patients experiencing serious illness: A Greek perspective

Dear colleague,

I am engaged in a research project following a group of patients through the experience of advanced cancer. The study, part of my PhD, has been funded by the Greek Government (by giving me a scholarship to study abroad) and is being supervised by academic staff from Kings College London. The aim of the study is to explore the care patients with advanced cancer receive and develop a better understanding of their treatment and care experience. The study has received the approval of the Kings College Ethics Committee and the “Agios Savvas” Oncology Hospital Ethics Committee. The approval numbers are...

As part of my study I intend to observe patients from the time that curative treatment comes to an end and until their death approaches. I also propose to follow them as they access care from different care settings during this time. I will principally be observing what happens to patients during these times and will make a record of my observations. I will be approaching patients and their families on your ward to ensure they are happy to take part.

Observation of patients will by necessity involve observing their interactions with healthcare professionals. I would like to seek your permission to include you in my research. I will work hard to ensure I remain as unobtrusive as possible and you can ask me to stop observing and to leave the area at any time you feel necessary. If you are not happy to be observed please let me know the next time I visit the unit.

I may ask to interview you about your experiences with this group of patients. The interview will be tape recorded to ensure that I record your views accurately and I will arrange for it to take place in a private area of the hospital. It may be that you don't wish to take part in both these activities - the observation and interview. If you would prefer to take part in one and not the other this would still contribute to the study.

No member of staff will be identified personally, and I will ensure that the location of the research will remain anonymous in any written report.

I am happy to provide you with a summary report of the study when it is completed.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will be asked to consent orally if you agree to be observed and you will be asked to sign a consent form if you agree to be interviewed. If you decide to take part you are still free to withdraw at any time and without giving a reason.

In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through King's College London's 'No Fault Compensation Scheme'

Thank you for taking the time to consider this request. If you do agree I will provide a consent form for you to sign.

I am happy to answer any questions you may have about this research study before you make a decision about whether to take part or not. I can be contacted on the number...

Yours sincerely
Despina Anagnostou
Doctoral Research Student
King's College London

Professor Alison Richardson
King's College London
Florence Nightingale School of Nursing and Midwifery
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA

Monday 20th June 2005

Dear Alison

04/05-122 An ethnographic study of the care of patients with advanced cancer: A Greek perspective

Thank you for submitting the above application which the College Research Ethics Committee considered at its meeting on Thursday 16th June 2005. The Committee would like to congratulate you on a well thought out and completed application. I am happy to inform you that this project has received full approval and would ask you to note the following points:

1. We would advise you to consult with the KCL Legal Compliance team about collecting data and whether there are any special arrangements/ exemptions applicable in Greece.
2. Please check with the Greek authorities that the College's 'No-fault' compensation scheme is accepted in Greece.
3. Please replace '12 months' with 'a few' months in the paragraph 4 of the Patients and families information sheet to reflect the need for flexibility.

Please note that you should use your CREC reference number (given in the title of this letter before the study name) on the study Information Sheet and recruitment literature and in all future correspondence with the CREC regarding this application.

Please read the enclosed Notes for Investigators of Approved Projects and the college guidelines on record management. These can be found by accessing the KCL website at <http://www.kcl.ac.uk/depsta/iss/archives/recman/toolkit0.html> and reading Fact Sheet 15 'How to manage academic research records'. Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

For your information ethical approval is granted for a period of two years, after which point you will be reminded to apply for an extension of approval (please note however that a full re-application will not be necessary unless the protocol has changed).

When making future submissions, please note that the new application form should be used for all projects. The new form is available from the following location:
<http://www.kcl.ac.uk/research/crec/appform.html>.

We wish you every success with this work.

With best wishes

Yours sincerely

Professor Anthea Tinker
Chairman, College Research Ethics Committee

c.c Despina Anagnostou

Appendix 6: Procedures for applying to the hospital Scientific Committee

The procedures for applying in both committees King's ethics committee were clear; the form and guidelines of the application were offered online. With the help of my supervisors I gained approval for the study in July 2005(Appendix I). In contrast, I could not find any relevant information for the hospital ethics committee. I was informed that there were no specific forms or guidelines to follow and that I would have to make my own. As I could not identify any relevant information, I decided to discuss my proposal with some colleagues, academics and researchers who had performed research within this specific hospital. Wilson (1985) advised researchers to use friends, contacts, colleagues, academics to help with the access; the route should not matter. The suggestions offered to me were based on the fact that the health care settings in Greece are not familiar with qualitative research and some aspects of it (table 1).

Table 1: suggested changes to the application for the Greek Scientific Committee

<ul style="list-style-type: none"> • The sample size was too small; it should be presenting in a way that is would look bigger: <i>Maximum 100 participants- patients, family members and health professionals involved in their care, instead of 15 patients , their family members and health professionals involved in their care</i>
<ul style="list-style-type: none"> • Written consent forms are not used often because they cause more anxiety to patients and I should be prepared for hospital's opposition
<ul style="list-style-type: none"> • Observation is not considered a scientific research method and thus I should explain this method more extensively well as the role of qualitative research in health care.

Following their suggestions, I changed the description of sample size as mentioned above. I also explained clearly that I would pilot the consent forms and only if they were accepted by the patients I would keep providing them. Otherwise, I would inform the Kings Ethics Committee about it in order to make the appropriate changes. Finally, I included two paragraphs underlying the contribution of qualitative research to health care and explaining observation as a scientific method of data collection and its role. These suggestions were proved very helpful, as I was requested to defend these points orally to the ethics committee and I was prepared to do so. They also gave me an insight to the research culture of health care (a nurse and not a doctor, being modest, respecting authority), which I could not identify through literature. (see also gaining access section). Approval of the study by the local ethics committee was granted after more than three months of my application, in December 2005.

Appendix 7: Information sheet for patients and families

Study: A study of the care of patients experiencing serious illness: A Greek perspective

Patients and families information sheet

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. You have been given information about the study because you have been ill for a while now and you have been admitted to hospital several times in the past. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

The study has been funded by the Greek Government (by giving a scholarship to the researcher to study abroad) and is being led by the researcher in connection with King's College London where she studies. The King's College Ethics Committee and the "Agios Savvas" Oncology Hospital Ethics Committee have approved this information sheet. The approval numbers are...

The purpose of the study is to explore what care patients who experience a serious illness receive. The study aims to understand patients' perceptions of their needs and understand their experience of being seriously ill. It is also interested in exploring whether patients are satisfied with this care they receive and describe their everyday life and how it has been affected by their illness and the care they receive.

The researcher hopes to accompany you over the next 12 months when you have medical appointments or you are going to the hospital so that she can gain an understanding of what is happening to you and observe the care you receive. If you would like, she could visit you at home to see how your life is outside hospital. She is also interested in how you and your family cope with the situation and thus she asks permission from your family to observe them as well. She may take some notes during the time she is observing you.

The researcher also hopes to conduct some interviews with you and some family members, so that she can gain a better understanding of your opinions, thoughts and perspectives. Interviews will be taped and transcribed by the researcher to help her analyse them properly, and if you would prefer she could take notes instead. At any time you may ask for the tape to be stopped or for her to stop writing notes. There are no right or wrong answers, or bad and good opinions. Your own personal thoughts and feelings are of interest. Conversations during the time the researcher will be with you may also take place, particularly when she would like to clarify issues occurring from the observation.

We cannot promise that taking part in the study will be of direct benefit to you, but an important part of the study is to find out what patients think of their needs and the care they receive, so that the results from the study will help health professionals to determine more accurate and effective ways to help future patients.

Any information which is collected about you, or that you provide during the study, will be kept strictly confidential. The information we collect will have your personal details removed so that you cannot be recognised by it. Information, including tape-recorded information, will be held securely for the period the study is carried out. The tapes will be destroyed at the end of the study and other information destroyed seven years after its completion.

When the findings have been analysed, they will be prepared for publication in nursing and medical journals, and for presentation at conferences. A summary of the results will be available for all study participants.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through King's College London's 'No Fault Compensation Scheme'.

Thank you for reading the information

The researcher will be happy to answer any questions you may have about this research study and can be contacted on the number...

Despina Anagnostou
Doctoral Research Student
King's College London

Appendix 8: A cognitive linguistics approach of directive speech acts in a health care context: Dying patients' expectation

A COGNITIVE LINGUISTICS APPROACH OF DIRECTIVE SPEECH ACTS IN A HEALTH CARE CONTEXT: DYING PATIENTS' EXPECTATIONS

Vassilaki E. & Anagnostou D.

Applying linguistic analysis to health care communication has aroused an increasing level of interest during the last decade as one can see from works and papers published in linguistic, social science and medical journals⁶.

Nonetheless, the emphasis in the present study is on communicative interactions, rather than narratives, and it is primarily concerned with the ways patients at the end of life interact with their environment. Furthermore, We attempted to apply a model of speech act analysis developed within the Cognitive Linguistics tradition, assuming that not only the content of patients' linguistic output but also their actual wording of their communication can reveal aspects of their perceptions regarding their expectations from their environment.

Data

Data were originally collected for the purposes of a longitudinal study on the perceptions of patients at the end of life about their quality of life in Greece. As the study followed an ethnographic approach, the collected data reflected the time spent with patients and their families over a period of 20 months, whilst following them during the last months of their life, as well as their encounters with health care professionals. Fieldwork took place in two medical wards and a day care clinic of an oncology hospital, the emergency room of two general hospitals and the patients' homes. The data consist of transcriptions of semi-structured interviews, conversations and interactions between patients, health professionals and family members, which were recorded during participant observation

⁶ for an illustrative review of them, at least until 2003, see Candlin & Candlin 2003, see also contributions in journals: *Patient Education and Counseling, Communication and Medicine*

(989 hours of participant observation next to the patients). Additionally, field notes were kept during participant observation.

Theoretical background

Linguistic actions, by means which a speaker typically directs or influences a hearer's subsequent behavior, are described as directive speech acts⁷. Within the limits of this study we focus on a subcategory of these, namely requests for action. Frequently used in a variety of everyday encounters, requests can be a rich source of interactions with respect to socio-cultural observations, since the choice of structures open to speakers is not entirely free but "it conveys different attitudes, different social norms and values, as well as personal differences"⁸.

In classic speech act theory, requests can be realized either directly or indirectly⁹. However, directness is matter of degree: requests can be expressed with a variety of structures classified as direct (e.g. imperatives), conventional indirect (e.g. modal questions of the type *can/ could you close the door?*) or non-conventional/ pragmatically indirect (statements like *there's a draft in here*)¹⁰.

In our analysis we propose a somehow differentiated bipartite specification of requesting strategies based on two criteria:

- a) the degree to which the action under request is rendered explicit in the utterance and whether there is clear reference to the agent of the action¹¹
- b) the degree to which the interpretation of the utterance as a request is cognitively salient in the context of the utterance¹².

⁷ Verschueren 1985, 152

⁸ Sifianou 1992, 101

⁹ depending on whether the linguistic means used in the utterance that performs the speech act is the "illocutionary force indicating device" typically associated with the specific kind of speech act (i.e. orders are realized by the imperative mood or imperative sentence type).

¹⁰ Blum-Kulka 1989

¹¹ what Clark 1979 calls transparency, see also Haverkate 1979, 101-102 in le Pair 1996, 654 "utterances that contain a specification of the requested act and at the same time make an explicit reference to the interlocutor are the most direct requests".

¹² further supported by psycholinguistic evidence, see Giora 1997 for the graded salience hypothesis.

This way, in our description, we examine direct and conventional indirect requests in a similar fashion -we could term this group “explicit requests” as opposed to existential statements or hints, namely non-conventional indirect requests, or “implicit requests”.

Of the approaches proposed from a Cognitive Linguistic perspective on the semantic make-up of directive speech acts, we have adopted Pérez 2001 and Pérez & Ruiz de Mendoza 2002 proposal: directives are considered to be understood and produced by speakers in terms of a propositional Idealized Cognitive Model (ICM), the parameters of which include various socio-cultural aspects involved in the conceptual make-up of these speech acts¹³.

More specifically, in the case of a request, (see Pérez 2001, 115-130) an agent, prototypically the addressee, is imposed up to a certain degree (degree of optionality) to realize in a future point of time (time of action) the action requested by his/her interlocutor. The relationship between the participants can vary in a hierarchy of authority (degree of power) as well as in a continuum of intimacy (degree of social distance). Prototypically, a speaker performing a request strongly wishes the state of affairs expressed in the predication to take place (high degree of speaker’s will) and, s/he would “benefit” from it. However, the fulfilment of a request prototypically involves a “cost” to the addressee, some unplanned or negative effect in his/ her course of action (degree of cost-benefit)¹⁴. Finally, requests can be performed whatever the degree of formality of the context.

¹³ ICMs work as abstract domains (Langacker 1987) “while highlighting the not-so-simple relationship between a semantic domain and the external experience it used by the mind to grasp” (Clausner & Croft 1992,2).

¹⁴ “The addressee will have to invest time and effort in doing something without getting any benefit in return” (ibid, 118)

One more thing to be noted in the case of request is that there are certain correlations between the cost-benefit parameter and the social distance one: what is considered costly for an interlocutor rather low in a scale of intimacy may be taken for granted when there is a high degree of intimacy between the participants. Moreover, as Sifianou 1992 notes, social norms prevailing in each

All the above mentioned parameters, involved in the characterization of a request, comprise the ontology of the request illocutionary ICM, whereas the relations and interplay between these variables constitute its structure. In everyday interactions these parameters are activated and attributed values either through certain linguistic forms and/ or by the context of the interaction. Since ICMs can be a source of prototype effects, it is expected that more prototypical requests would be linguistically or even socio-culturally conventionalized¹⁵.

In the case of “explicit requests” -the ones that are expected to be linguistically conventionalized- patterns of their realization can be described as grammatical constructions (in the sense of Langacker). In line with more recent studies¹⁶, we assume that grammatical constructions “are not arbitrary units of form and meaning” but their constituent parts do play a role in their pragmatic force.

In this sense, the degree of imposition was conveyed by explicit directive constructions results from the temporal and modal specifications of the verb form of each construction. Tense and modality in Langacker’s Grammar are “grounding elements” that locate the action described in the predicate¹⁷ in terms of epistemic notions such as time and reality vis-à-vis the “ground” (the speech event and its immediate circumstances). In a previous study on directive constructions in Modern Greek, we have argued that the more proximate to reality (the here and now of the speech event) a construction is, the greater the degree of imposition and vice versa. Hence, imperative constructions are more impositive than present tense interrogatives, which in turn are more impositive than future or modal interrogatives.

On the other hand, in real time interactions speakers often resort to less explicit or non-conventional ways to demonstrate their requests. Speakers may opt for a certain degree of indeterminacy in order to preserve social norms and practices and avoid confrontation. Addressees may perceive and interpret such utterances in ways that serve

language community or the emphasis put in tightening in-group relationships may alter significantly the degree to which a requested action is estimated as costly.

¹⁵ see also Marmaridou 2000, 216

¹⁶ e.g. Panther & Thornburg 2005 or Cornillie 2005

¹⁷ the designated process, in Langacker’s terms

their communicative intentions/ interactional goals. Then the force of the utterance (whether it would be treated as a request or an assertion) becomes a matter of negotiation in the course of the interaction.

Pérez & Ruiz de Mendoza 2002 argue that in order to account for such cases of indirect requests one needs to refer to an independent ICM of social interaction, the ICM of cost-benefit which contains information about some of the cultural conventions of what constitutes polite or -we may call it- sociably acceptable behaviour in, at least, most Western cultures. According to the 1st convention:

“If it manifest to A that a particular state of affairs is not beneficial to B, and if A has the capacity to change that state of affairs, then A should do so”.

Applying this convention in language use can provide the cognitive motivation for the interpretation of a declarative sentence of the kind *I am hungry* as a request. Such an assertion, depicting a state of affairs that is not desirable or beneficial to a speaker A, causes the hearer to react in order to do something to change this state of affairs, if he does not want his behaviour to be perceived as impolite or socially unacceptable¹⁸. In the absence of linguistic conventions, socio-cultural internalized conventions are activated for the creation of meaning.

What follows is an application of the model proposed to the data whilst attempting to interpret why speakers have chosen each specific construction in the realization of each request.

Analyzing the (selected) data

Within the limits of this presentation, we examined 80 interactions from 7 different patients (4 males, 3 females) and from different stages during their stay in the hospital and their illness trajectory. About half of them contain requests for action to a family member, most often the patient's wife. The other half of the requests are addressed to health professionals, mostly nurses.

¹⁸ Another interpretation could be the one proposed by Panther & Thornburg (Thornburg & Panther 1997, Panther & Thornburg 1998, Panther & Thornburg 2005). According to them, such a statement activates the “before” part of the speech act scenario and metonymically links it to the “core” part (the request: give me something to eat). But speech act scenarios are included in the ICMs of directives; see Pérez & Ruiz de Mendoza 2002 for arguments.

Given that requests are placed “half way between the minimum optionality offered by directives like orders or threats, and the maximum optionality which characterizes the acts of warnings, advising and suggesting”¹⁹, it seems that the relative degree of optionality is actually determined by the interplay between the parameters of cost-benefit and social distance. We expect that the higher the cost for the addressee and the more the social distance between the participants, the higher the degree of optionality of the request would be. On the other hand, lower cost for the addressee and smaller social distance would result in requests with a lower optionality degree. Still, if the cost is considered high, even in interactions between intimates (minimum social distance), the degree of optionality seems to increase significantly.

The degree of optionality is reflected linguistically in the choice of the language forms used: low optionality requests would be realized by more direct constructions (more immediate structures, in the sense adopted in the present analysis), high optionality requests would be expressed by more elaborated constructions, or more distanced from the reality of the speech event.

The use of mitigating devices (vocatives, adverbs etc) may “soften” the impact of the request but, we believe, it does not affect the optionality degree communicated on behalf of the speaker.

a) Family members

When patients address their closest family members, especially their main caregiver, we expect them to employ direct constructions: In fact, imperative constructions seem to be predominant in our sample.

These requests may refer to simple tasks that the patient can not accomplish by himself because of his physical situation.

‘Oh, I told you I want it [a sweet]; give it to me’ (Giorgos, WS: 10122)

Pay attention to the drip when it is over (Sotos, WS: 98721).

¹⁹ Pérez 2001, 120, see also Searle & Vanderveken 1985, 199, Lyons 1977, 749

A number of them are aimed at the addressee asking them to refrain from some action that is not desirable or agreeable to the speaker.

YOU found again an opportunity to nag at me, leave me alone (Giorgos, WS: 100228)

Don't upset me again (Pablo, WS: 10055)

Don't speak guys, I cannot take it anymore, let me rest (Sotos, WS: 98939)

Even if in an English speaking culture such use of imperatives may sound “rude”, in the Greek linguistic community “there is a strong predilection for imperative constructions”²⁰ to express a request, especially between family members with established roles and duties. If this is true for routine everyday interactions, it becomes even more prominent in the particular setting, where the perceived duty of a family member providing care should be to work on the conditions that intend to make the patient's state more comfortable and relieve the uneasiness caused by his physical condition. What is more, despite the fact that sometimes these imperatives could be interpreted as orders, addressees treat them as requests and negotiate whether they will fulfil them or not. An illustrative example is the following interaction between a patient and his wife.

Patient: Jenny, I am in pain, leave me alone

Wife: But I need to sort out your pyjamas because you have started developing a pressure sore

Patient: Why don't you understand me? just leave me alone; give me a break

Wife: But you are developing a pressure sore and there is a risk of infection (Pablo: WS, 10123)

Surprisingly, only a couple of other request instances are realized by present tense interrogatives. We have argued in a previous study on directive constructions in Modern Greek that the present tense interrogative construction is the most characteristic realization pattern in the expression of request in Modern Greek, used in a variety of

²⁰ Sifianou 1992, 133, see also Vassilaki 2006, 210-213

contexts and communicative situations²¹. However, we cannot simply sustain an argument that there is a preference for imperatives rather than interrogatives due to the specifications of the setting, and would want to test the validity of this hypothesis in a more extended data set .

At the other end of the scale - from explicit direct requests to more implicit expressions - there are a few instances of the latter, describing a state of affairs not desirable or unpleasant for the speaker. What is really noticeable in these occurrences, though, is that these utterances, especially when addressed to family members, have exactly the same impact as explicit direct requests. Due to the specifications of the context and the roles assumed of the participants, what is perceived as highly beneficial for the speaker -even if not rendered explicit- regresses the optionality of the implied request to the point it is perceived by the hearer as carrying the same degree of imposition as an imperative.

b) Health care professionals

When addressing nurses, constructions are more elaborated with the exception of one of the patients in the sample data. Nurses have established roles and they are expected to act in ways that can improve a patient's wellbeing. Hence, requests of this kind would be considered of low cost to them, since the requested actions fall within their duties. However, there are two other parameters that seem to play an important role in this case: social distance and power. Even though most members of the nursing staff have developed a degree of familiarity with the patients, they are not perceived by patients as intimately as family members. Moreover, the patient-nurse relationship is assumed to be an asymmetrical one, due to the professional power attributed to healthcare staff because of their knowledge and expertise. So, we find instances of requests that are realized by present tense interrogatives (*can you pass me the water please?*) or less direct constructions of the kind *can/ could you + VP* interrogatives.

Could you give me the thermometer because I cannot reach it? (Giorgos, WS: 10085),

²¹ In fact, such constructions (example from the data: *mou planeis to zele?*, literally, *are you passing me the dessert?*) are the Greek equivalents in terms of pragmatic import of the English *can you + VP* interrogatives (so, the actual translation would be *can you pass me the dessert?*)

If you could please check the wound on my leg, because it hurts a bit, maybe if we could change the place of the pillow (Pablo, WS: 101256),

Nonetheless, if the situation requires immediate action, imperatives are also used:

I cannot breath, do something please, do something (Giorgos, WS: 100934)

Help me, help, I am drowning (Sotos, WS: 98776).

We also have to mention that in all occurrences the T form (second person singular) is used²², marking small social distance and informality present in the relationship.

An interesting case is that of an elderly patient who employs imperative constructions to perform requests to all healthcare professionals. It seems that his age and his social status minimize power asymmetry (he used to be the mayor of his town, a leading and respectable personality in his community)

'Doctor, come here. Tell me what is happening to me' (Sotos, WS: 98021)

Still, where the cost of the action under request is estimated as relatively high, since it does not fall within the perceived duties of a nurse Sila asks the nurse to make her a cup of coffee- a sequence of less to more direct constructions is used:

S: May I ask you a favour before you go and God bless you? (Subjunctive interrogative)

N: what is it Mrs Sila?

S: Will you make me a cup of coffee that I fancied? (Future interrogative)

N: you want coffee?

S: Do me this favour (imperative)

Non explicit request instances are also found in this group of interactions. However, there is a difference in the way they are treated by the addressees: while family members

²² Greek verb morphology marks T and V forms by verb number endings, where second person plural endings are the formal counterpart of second person singular

perceive such utterances as requests for immediate action, nurses attempt first to assess the importance of the situation and then decide about future action.

Patient- Daughter

P: I am in pain

D: Shall I ask for a painkiller? (Tamara, WS:10008)

Patient- Nurse

P: Hey, you

N: What is it Mr?

P: I have a sore throat

N: Is it very uncomfortable?

P: I can't [do] anything

N: You mean, you cannot drink anything?

P: Yes

N: Ok, I will see what I can do (Natasha, WS10299)

c) Doctors

There are relatively fewer doctor-patient interactions found in our sample that contain either an explicit or non explicit request addressed from the patient to the doctor. These instances contain no explicit requests either describing an unpleasant situation, or expressing a desire.

*Doctor, I have a problem in my head, I guess two. I cannot take any more treatments
(Sila, WS: 90432)*

Doctor, I want to go, I want to go home (Sotos, WS, 09321)

If you ask me what I want, I would say I want painkillers, something so I would not be in pain (Pablo, WS, 101259)

Only in the case of the elderly man, a direct request for action is followed by a direct request for information.

P. Doctor, don't go; stay that (because) I need to speak to you

D. what do you want Sila?

P. Tell me, my doctor, how am I doing? What is going to happen?

(Sila, WS: 98218)

The fact that there are less instances of patient-doctor interaction recorded can be explained by taking into consideration several aspects. The participants of this study were patients with cancer at the palliative phase of their illness and most of their admissions were routinely planned for treatment and routine monitoring tests. Therefore, diagnostic or assessment communication was not often required. Additionally, they were at an advanced stage of disease, which means that patients were very tired and thus, very selective in their communication. Given the fact that in Greek culture the doctor's role is associated with curative treatment rather than palliative care, patients appear to have limited their expectations of doctors. Nonetheless, decisions to be reached were usually negotiated with the family members.

Conclusions

To sum up, exactly because of their nature, directive speech acts cannot be adequately accounted for unless all social, cultural, contextual and linguistic aspects are taken into consideration. Propositional ICMs as types of knowledge organisation structure, can offer a tool to describe how directive speech acts are produced and understood by speakers. Applications to data from various specific contexts can shed light on the role played by norms and conventions of the subculture of a specific setting and the wider culture of the linguistic community in the interpretation of utterances and the creation of meaning. The preliminary findings from this study in a health care setting in Greece point to such an interpretation.

Due to health care context specifications, a high degree of imposition is not exclusively or necessarily conveyed by explicit direct structures; a statement describing an unpleasant state of affairs for the patient, can be equally effective. Not much has to be said when it comes to relieving human pain. On the other hand, in the Greek speaking culture, an explicit direct imperative can be employed as a reminder of a duty without being offensive.

As regards the ethnographic point of view, the linguistic data provides evidence on the predominant role played by the family as an institution in Greek society. Family members are expected not only to support, but also to provide, the basic care for the sick member, at whatever cost. Further research on more extended interactional data will provide us with a better elaborated picture.